

The Application of Paolo Freire's Pedagogy in renegotiating HIV Stigmatised Identities: A Study of DramAidE's Health Promotion Project (HPP) at the Durban University of Technology (DUT).

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Signed.....

ABSTRACT

Diagnosis with HIV disease is associated with a negative life event which impacts on health, longevity, reproduction and sexuality. Given the impact of disease stigma on prevailing constructions of masculinity and femininity, gender expectations are found to play an increasingly important role in prevention. In contexts in which increasingly more young people are living with HIV there is a need for appropriate sex-education, support for dealing with sexuality and self-identity with HIV. This calls for a prevention approach that gives a voice to those who have previously been marginalised and necessitates a move away from prevention approaches that are didactic and use top-down shifts in policy and regulation as a means of encouraging risk reduction.

This study explores DramAidE's Health Promotion project which locates young people who live openly with HIV in the centre of an HIV/AIDS mitigation project so that they can provide leadership and engage campus communities in HIV/AIDS related activities and events. Unlike most higher education stigma reduction efforts which draw on a model of "liberal enlightenment" in which communications experts design projects with the intention of correcting inappropriate thoughts and actions, this project avoids, what Paulo Freire (1972a) calls a 'banking' approach to health (Maluwa, Aggleton, and Parker, 2002).

Participatory action research is associated with democratic struggles and is used in this dissertation to encourage resistance to stigmatising attitudes which are encoded within current prevention approaches. The findings suggest that peers exposed to the Health Promotion project engage with gender and prevention issues in a highly critical way. Peers living and affected by HIV have developed a context specific set of norms which encourage testing. An innovative approach to prevention has been adopted in which peer leaders living with HIV provide an alternative model of care and support which is community supported.

LIST OF ACRONYMS

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
DUT	Durban University of Technology
HIV	Human immune virus
HP	Health promoter
FS	Female student
MS	Male student
TO	Theatre of the Oppressed

CHAPTER 1 - BACKGROUND TO THE STUDY

OVERVIEW

In this chapter argument is made for HIV prevention interventions to consider how best to mobilise young people to consciously refashion 'alternative' notions of practice which hinder prevention. Critique of HIV prevention suggests that there should be less emphasis on prescriptive education that proscribes lifestyle changes and that there is a need for better understanding of identity, risk practice and the context in which practices are constructed (Kippax, 2005).

BACKGROUND TO THE STUDY

Recent estimates of the incidence of HIV amongst youth suggest that 7.6 million people who are of university going age group (18-25 year olds) are HIV positive (Ndinga-Muvumba and Pharoah Eds., 2008). It is believed that HIV will negatively affect the future development of the county's leadership and is therefore considered a priority in higher education (HEAIDS, 2004). If the epidemic is to be effectively addressed it is vital that young people know their HIV status, minimise (re) infection, monitor their status and access treatment care and support. Even though with early diagnosis and treatment, HIV is considered a chronic but manageable disease, many sexually active people prefer to avoid finding out their status as the threat of being robbed of one's sexuality and the fear of dying are overwhelming fears (Fako, 2007).

Besides the biological implications of HIV, the social construction of the disease creates a stigma that strikes at the core of identity as it is coded around idealised hetero - normative¹ ideas about gender and sexuality. It is hardly surprising given the negative ideation surrounding people with HIV that there is a 'culture of silence' which makes it difficult for people to disclose their status to their partners and to access treatment care and support (Morrell, 2000). People living with HIV are imagined in some contexts as sexually deviant in some way or as having no right to a sexual life (Crawford et al., 1997). HIV diagnosis is thus considered a negative life event that threatens sexual identity and

¹ Hetero-normativity is rooted in the idea that male and female gender norms are biologically determined and adhere to predetermined scripts. These beliefs are encoded in language, in institutional practices and everyday life through the performance of narratives. These narratives include ideas about the 'normal' family, monogamy and sexual roles (Butler, 1994:33).

life. Faced with the uncertainties about life and the stigma associated with HIV it is unlikely that people will be able to renegotiate their identity in an affirmative way, particularly as there are few role models of disclosure on which to draw (Crawford et al., 1997).

In contexts where there is an increasing population of people affected or living with HIV counselling and testing is touted as the best means of prevention (see van Dyk 2005; Birdsall et al., 2004). Prevention is essentially premised on the assumption that if people are educated to modify their behaviours they will avoid (re) infection with HIV. The argument for knowing one's HIV status is based on the rationale that if one is 'negative' one will practice prescribed behaviours and remain so. If on the other hand, one is 'positive' lifestyle changes must be adopted (Kippax, 2006 citing the World Health Organisation, 2004). Those who are diagnosed HIV positive find it difficult to adopt a revised lifestyle in which they are expected to not engage in unprotected sex, must refrain from consuming alcohol and drugs and are encouraged to adhere to healthy diets, lifestyles and drug adherence. Men especially seem to shy away from this revision of their identity which probably accounts for health services remaining the domain of women in which seven out of ten adults accessing antiretroviral therapy (ART) in South Africa are women (Robins , 2007 citing JCSMF, 2006). This far outstrips the proportion of women versus men that are HIV positive. (Human Sciences Research Council, 2009)

Increasingly HIV/AIDS interventions expose men and women to HIV prevention and treatment messages that call for "responsible" sex and lifestyles. These often fall on deaf ears as men and women who are sexually active are often in denial that their relationships expose them to risk. They also often have little choice in negotiating safer sex practices and are vulnerable to HIV infection due to socio-economic and cultural barriers.² It is those who are considered most at risk or vulnerable³ to HIV and engage in risky sexual practice who feel stigmatised against by prevention messages which criticise their lifestyles and

² Diagnosis with HIV is perceived as 'moral shame' that comes from young people going against expected sexual norms sanctioned by society. HIV is also often considered a consequence of not observing cultural norms and traditional customs associated with initiation and funerary rites (Ashforth, 2001).

³ The concept of 'vulnerability' features prominently in AIDS literature and has become synonymous with the situation of women and youth. 'Vulnerability' is defined in terms of situational contexts in which norms come into play marked by circumstances that are marked by frailty, disempowerment and insecurity and the likely inability to fend off possible infection or to cope with its effects (Marais, 2005)

which urge them to 'change' their 'behaviour' (Kippax, 2006).⁴ There is an anomaly in behaviour change because the action implied by this often cannot be governed by intentional action on their part. 'Behaviour' refers to all actions that people do. These are often defined by pre-conventions or situations that are socially derived and not contingent on what is in the mind of the individual. It is for this reason that this study uses the term 'practice' which refers to the social aspect of action which implicates social rules and roles in defining action. This further suggests that 'practices' are beyond our own understanding and serve serving functions beyond our own immediate knowing (Kelly et al., 2001).

As the realities we inhabit are brought forth from the language we use, they are then kept alive and passed along in the stories that we live and tell. Stories are the means by which we organise our experiences and our memory of human happenings mainly in the form of narratives – stories, excuses, myths, reasons for doing and not doing, and so on (Bruner, 1991:4). .⁵

Gender narratives are often made up of social norms, conventions, tradition and rules that govern conventions or accepted lifestyle narratives (Doyal and Harris, 1985) Gender narratives often include rituals, customs or ceremonies and determine the particular way a person lives their lives.⁶ This means that they often unconsciously accept certain ways of being and conform to these conventions. Pre-existing narratives about how young men

⁴ In the South African context in which dual cultural beliefs/systems often exist side by side "complex interactions of culturally determined sexual and gender roles and how tensions between the modern reality of HIV/AIDS and the desire to maintain cultural norms, interface in ensuring successful patrimony (Steinberg, 2008).

⁵ Post modernists focus on how the language that we use 'constitutes' our world and beliefs. Freedman and Comb emphasise that speaking is not neutral or passive and that each time that we speak we give legitimacy to the distinctions that those words bring forth. Given that the 'logic of language lends an air of 'logic' to our perceptions and descriptions of the social world we tend to confuse 'logical' with 'real' (1996:26). This presents, however, the opportunity to challenge the understanding of 'knowledge' as something that exists independently in people's heads and to recognise that it is constructed in the activities people do together.

⁶ The significance of this for challenging gender norms is that in changing language that is conventionally used in certain stories, we can change the stories that legitimate certain beliefs and attitudes. This is because meaning is not carried in the word by itself, but by the word in relation to its context. The reason for this is that no two contexts will be exactly the same which makes the meaning of the word indeterminate and something that to be negotiated between two or more speakers.

and women should be brought up, how they should be socialised and how they should act become a measure of how they measure up to an idealised norm. These narratives are reinforced in schools, within the family and in intimate relationships. Epstein (1995) argues that the relationship between gender and sexuality is critical to an understanding of sexism and heterosexism in education, pointing out that sexism cannot be understood without an analysis of its relationship with heterosexuality. In contexts, where young boys are often socialised from a young age to accept gratification as a right of their patriarchal power, it is a natural progression to expect that sex is a 'right' which should be 'demanded'. This often leads to the reinforcement of practices that include multiple partners, sexual coercion and unprotected sex. In modern contexts this has led to male sexuality routinely being blamed for the spread of the pandemic. A consequence of perpetuating negative stereotypes about male sexuality which shames 'normal' ways of behaving is likely to result in defiant behaviour and ensure that men continue to avoid accessing treatment, care and support service. Perpetuating common narratives about male sexuality makes it difficult to address gender issues and envision alternative identities (Ratele, 2008; Robins, 2008).

Research suggests prevention campaigns need to place greater emphasis on programmes which deconstruct cultural and social barriers which contribute to the avoidance of delays in testing and treatment. Mass media campaigns, however, continue to proliferate in size and scale (Leclerc-Madlala, 2002; Petersen et al., 2005). As, Lindegger and Durrheim (2001) argue: "changing the relationship in masculinity and HIV risk is about far more than just changes in behaviour and technology, but rather about transformation in the very identity of men". It is for this reason that researchers motivate that prevention recognise the complex emotional and cultural codes that shapes the ideology of what it means to be a male or female (Fontdevila, 2006). Researchers therefore agree that that one of the best means of developing successful and innovative HIV prevention programmes is for young people to enhance their understandings of sexuality and the manner in which dominant norms contribute to the spread of sexually transmitted diseases (Preston-Whyte 2003; Campbell et al., 2005). This calls for the recognition that men and women are often complicit producers of sexual narratives and norms. Narratives which reinforce the notion of women as "desexualized beings trapped in men's power and promiscuity ... waiting to be infected" need urgent reconsideration (Berger, 2004:47).

The challenge for young men and women is to confront ways in which power has become implicit in co-creating a culture of victim-hood in young men and women (Dobson, 2002; Adomako et. al, 2007). Connell's (1995) definition of masculinities is thus appropriated for the purposes of this study. This definition implicates men and women as active participants, complicit producers, consumers and performers in defining gender expectations and the social conventions that shape gendered power dynamics influencing health (Connell, 1995). The concept of different types of masculinity which are often reliant on each other to support their power makes it possible for HIV/AIDS prevention practices to envision that men can change.⁷ Whilst the concept of contesting masculinities has the potential to create different collective constructions of masculinity to thereby address contexts that foster conditions in which HIV flourishes (Epstein, 2007).

The problem of HIV stigma and its association with prevention therefore calls for innovative approaches which recognise that psycho-social and economic factors impact on social roles and contextualise sexual practice (Lindegger and Durrheim, 2000). The numerous studies that implicate gender imbalances and violence in the manner in which young people act out their sexuality recommend that more consideration needs to be given to how to address dominant hegemonic norms which often shape the shared intentionality to enact behaviour (Fako, 2007). It is with this in mind that this study examines contexts in which young people give voice to and become co-creators of revised understanding, attitudes and develop practices and conditions in which new norms unfold.

CONTEXT OF THE STUDY

The context of this study is the Health Promotion (HP) project which is a unique HIV/AIDS mitigation project in higher education that has developed a novel way to mitigate the impacts of HIV/AIDS. This project's approach differs from most HIV/AIDS interventions. Instead of endeavouring to change sexual practice through the prescription of certain

⁷ Hegemonic masculinity is understood as the pattern of practice that allows men's dominance over women to continue. This practice refers to "things done" and not just a set of role expectations. The concept implies that there is a normative understanding of what it means to be a "man" and it requires that other men position themselves in relation to this social norm. This is used as a means to ideologically legitimate the global subordination of women to men. The concept more importantly acknowledges that gender relations are historical and that their specific circumstances are open to change. This creates opportunities for different types of masculinity to compete with each other and for masculinity to change (Connell and Messerschmidt, 2005:832).

behaviours, the project encourages a community based response which explores, promotes and endorses positive practices that emerge from the expertise of the community to mitigate against HIV and related stigma (DramAidE, 2002; DramAidE 2006/7; DramAidE, 2008).

Unlike most stigma reduction efforts which draw on a model of "liberal enlightenment" in which communications experts design projects with the intention of correcting inappropriate thoughts and actions, this project is not designed by interventionists (Maluwa, Aggleton, and Parker, 2002). The project avoids a "banking" approach to health, as educationalist Paulo Freire once described it in *The Pedagogy of the Oppressed* (1972a), and is designed to encourage resistance to stigmatising attitudes. Although there is an established history of people living with HIV facilitating treatment and care, these tend to promote the rights of people living with HIV as a by product of other targeted interventions. What is unique about this project is that it locates young people who live openly with HIV in the centre of managing the HIV/AIDS programme so that they can provide leadership and engage the campus community in HIV/AIDS related activities and events (Crewe, 1997). Known as 'health promoters', they aim to play an important role to personalise the risk of HIV infection and demonstrate that HIV is a disease like any other (DramAidE, 2002; DramAidE 2006/7; DramAidE, 2008).

The Health Promotion project uses an approach that addresses HIV/AIDS on a deeper level than most other higher education institutional HIV/AIDS programmes. Most other higher education HIV/AIDS interventions are informed primarily by national and institutional HIV/AIDS policies which are implemented in the form of expertly managed standard peer education programmes (see Deutsch, 2003). The Health Promotion project on the other hand aims to mitigate HIV impacts informed by an approach that prioritises the development of a community 'context of care'. In a context of increasing numbers of people being directly affected and infected by HIV, 'care' involves the provision of health resources. It also refers to creating a climate for psycho-social well being, such as minimising discrimination and stigmatisation (Kelly, 2000). The rationale that underpins this approach is that when people living with HIV are cared for they are likely to become involved in being more open about their status and taking HIV protective precautions in their sexual behaviour (Campbell et al., 2007).

The defining characteristic of the subjects of this study is that they are peers of student age who with knowledge of their HIV status provide leadership to address HIV within the campus community. Representation of openly HIV positive young people in leadership positions provide valuable opportunities for people in their everyday lives to contest HIV stigma and gender discrimination (DramAidE, 2008). This process of social mobilisation, advocacy and support for those who are affected and infected creates awareness of prevention and care on a community level. This is supported by management who recognise the need for interventions to be driven by the community who can demonstrate a caring context (Kelly, 2001:9).

RATIONALE FOR THE RESEARCH

Morrell (2000) argues that silence is a symptom of unequal power in which normalising discourses rob phenomena of names. He puts forward that silence not only refers to that which is not talked about but also refers to that which is negotiated, regulated and polices the communicative space between people. It also does not accommodate certain subjects, issues or topics. HIV/AIDS prevention in educational contexts in light of this need to consider how interventions legitimate certain vocabularies and values while marginalising or silencing others (Morrell, 2000). Research concurs that young people living with HIV especially need appropriate sex-education, support for dealing with sexuality and self-identity with HIV (see Philpott, Knerr and Boydell, 2006; Shapiroa and Ray, 2007; Kelly,

Erdman and Cook, 2007). This calls for a prevention approach that gives a voice to those who have previously been marginalised and necessitates a move away from prevention approaches that are didactic and use top-down shifts in policy and regulation as a means of encouraging risk reduction. This type of approach should give critical consideration to the contextual factors around relationship behaviour, as well as, how sex, power and HIV are coded within social institutions and conventions (Dalrymple, 1987).

The challenge for peer education approaches is how best new knowledge, cultural actions, values and structures can be integrated into the lives of young people (Campbell et al., 2002). Increasing evidence suggests that social support and mentoring can reduce the residual effects of trauma of diagnosis with HIV and increase access to testing (Petersen et al., 2005). Given the strong influence of peer groups on young people attention needs to be given to interventions that develop the leadership of young people who are living with HIV. Especially those who are able to challenge pressures to conform, power inequalities, low self esteem and fears of social exclusion (MacPhail, 2003:141).

Leadership which is based on encouraging the participation of those who are most affected by HIV in dialogue on how best to address HIV stigma (and harmful gender norms) is most likely to succeed in creating an environment that is conducive to people talking about HIV and creating a supportive environment in which people feel that they can live openly with HIV (Kelly, 2000:59). This has the potential to create a social framework which is able to create a context in which new situations and pressures can mobilise change. More specifically, attention needs to be given to how young people are able to reconstruct and develop social and community rituals and traditions which create healthy normative contexts for male and female relationships (Morrison, 2005; Dalrymple and Botha, 2001). It is suggested that rather than refashioning people through individual level change programs there is a need for a collective re-negotiation of social/peer norms to challenge ideologically based assumptions about participation and dialogue.

The rationale for the application of Paulo Freire's pedagogy (1970) to this case study is its value in analysing the communicative contexts of the Health Promotion project. Especially, the approach allows challenging and countering repressive and oppressive social practices of HIV stigma. Freire's pedagogy is an appropriate method to counter a 'culture of silence'. His notion of "naming" the world forms provides a means of countering contexts in which people make assumptions that their misfortune is their fault and not part

of historically situated socio-cultural norms. In particular it is a way for men to counter blaming discourses and a means to access deeper emotions. Central to this is the acquisition of an emotional vocabulary as a means of countering 'illusion' and finding their true voices; ending the silence that entraps them (Morrell, 2000).

STRENGTHS AND LIMITATIONS OF THE STUDY

The study is 'theory generating' in the sense that it begins with a specific proposition and then explores how and if it works within a specific setting. The application of Freireian pedagogy has been found to be useful to address HIV/AIDS stigma in several studies and specifically those which confirm that effective treatment and care strategies require an understanding of the contexts in which stigma exists, for example, see Goldin (1994) and Campbell et al. (2007). The study examines stigma from the unique perspective of people living openly with HIV by looking at specific, contextualised details and the meaning thereof (Geertz, 1983). Because the purpose of the study is the exploration of the application of a specific theory it has the potential to enrich the case study context by shedding light on the change process involved in revising HIV stigma and harmful gender norms. The strength of a case study approach in the context of this study is that it has transferability value and the lessons learnt can be adapted to similar higher education contexts.

Having conducted research in 2007, this follow up study may be important in its own right. In particular it will be of use to investigate whether trends identified amongst peer educators are similar in the context of 2008. It will also be useful to examine the current context of the project in terms of the prior studies and evaluations which emphasise the social modelling aspects of the project rather than the transformation of community practice. It will also be useful to compare the findings of this study with studies that find that the application of Freireian pedagogy is not enough to bring about change due to the overwhelming mediating factors of power inequalities (Campbell and MacPhail, 2002).

Despite the interest of this study being to explore how male norms impact on access to HIV/AIDS services, the lack of participation in the main part of the study by males was found to be severely limiting. This necessitated a shift to examine male practices through the eyes of female participants. Vigilance on the part of the researcher was therefore crucial to ensure that the study bias was taken into account.

There was a shift in the research focus due to the self selection of the subjects of the study. These were young people who to lesser or greater degrees are living openly with HIV. The impact of this was both liberating and limiting in that it there was no participation by students who are not living with HIV. This shift may have been of some value and has the potential to add to current debates which show concern with regard to the role of pre-test counselling in attempts to encourage more people to find out their status in contexts in which treatment, care and support services have not been implemented as part of a more comprehensive response to health care with HIV (Koo et al., 2006).

Hemer, and Tufte, (2005) highlight that Freire's theory of dialogical communication is concerned with the intention of communication rather than forms of communication. In Freireian terms the principles that define the communicative context are important whilst the modality of communication is a product of that. This may pose a limitation on understanding how participation is developed to mitigate HIV stigma through the use of activities and events. It will therefore be important to draw on additional theories to counteract this limitation.

CHAPTER SUMMARY

This chapter highlights a need for education to address HIV stigma through processes of empowerment and transformation. This process of contesting dominant hegemonic sexual practices must of necessity have a strong human rights approach that involves HIV positive people who are living openly with the disease (Kelly, 2001). Such people should be situated in the 'centre' of the university system and not in the 'margins' if they are to address the complex social and cultural factors embodied in the system (Crewe, 1997; Kelly, 2001). It also argued that a solution to the problem of improving access to HIV services may be to enable structural, institutional and community level variables to support a social response which recognises communal norms in driving individual action (Parker, 1997). Young people living with HIV have the greatest potential to participate in 'change' in higher education settings by drawing on their own knowledge drawn from real life.

CHAPTER 2 – LITERATURE AND CONCEPTUAL REVIEW

OVERVIEW

This chapter outlines the history of the Health Promotion (HP) project and the development of the conceptual frameworks that inform it. A review of literature relevant situates the project conceptually in terms of behaviour change models of social change and suggests that a more contextualized approach is needed which acknowledges and makes use of community managed risk. The principle of development that underpins the project is discussed in relationship to the key concepts of empowerment, health promotion and development. A case study approach to the application of Freireian pedagogy is proposed. This uses relevant research to explore the value of the application of Freireian theory to the Health promotion project. In this process it is suggested that Freireian pedagogy does not sufficiently address certain change processes and that Augusto Boal's (1979) Pedagogy of the Theatre can be used to address the performative aspects of social change and usefully complement the Freireian approach.

THE DRAMAIDE HEALTH PROMOTION PROJECT

The aim of the Health Promotion (HP) project is to mitigate HIV in higher education by encouraging discussion and debate on HIV stigma and gender discrimination (DramAidE 2002/3; DramAidE, 2006/7). HIV positive student - aged peers live openly with the disease and provide leadership to engage campus communities in HIV/AIDS events which demonstrates in a practical way that HIV stigma is a community concern among those with HIV, in which each individual plays a role to develop a response characterised by social cohesion (DramAidE, 2008).

These peers are called 'health promoters' (HPs) and their role is to create an enabling environment for a community based response that promotes opportunities for involvement in HIV/AIDS on different levels (Parker et al., 1998; Parker and Kelly, 2000; Swanepoel, 2005). This means that the project moves beyond message-based, individual-orientated intervention by integrating a response that involves HPs endorsing health enhancing behaviours, by integrating HIV/AIDS responses by the institutional Higher Education HIV/AIDS Programme (HEAIDS) and involving senior management, staff and students in activities and events (DramAidE, 2004). The project is health promoting through facilitating 'healthy choices' by the creation of a supportive network of peer educators with a broader aim of initiating a social movement that promotes healthy lifestyles (Botha and Durden,

2004). Community activities and events provide opportunities for people to interact face-to-face, with peers of the same age, who are living openly with HIV. These activities and events involve big screen and 'Forum' events.⁸ Candle lighting and memorial ceremonies for AIDS activists are also held. A key purpose of the project is to encourage a critical analysis of issues related to HIV/AIDS through workshops and other activities (Frizelle, 2003). DramAidE views health promotion through the lens of a "paradigm of critical theory" to deconstruct common sense understandings of gender issues and to encourage those who have been voiceless to participate in addressing gender (Nduhura, 2004; DramAidE, 2008).

A history of the project

The current project is the outcome of several pilot programmes that have developed to refine the conceptual framework of the intervention. Originally DramAidE's schools programme 'Mobilising Young men to care' (2000) was initiated in response to the need to counter the cycles of violence and misogyny that existed in KwaZulu Natal schools (Botha and Dalrymple, 2001). The gender stereotype of men as brutish and uncaring, as well as the collusion of women playing submissive roles, has led historically to communication contexts that encouraged high risk practices (Kelly, 1996). The project is based on the understanding that these oppressive practices are often as a result of social and cultural norms which maintain unequal and oppressive relationships. Facilitators drawn from local communities continue to research the potential of workshops that will encourage young men and women to analyse communication contexts and to identify problem behaviours (Botha and Durden, 2004).

Influenced by the 'mother programme' DramAidE, the project developed with the understanding that HIV/AIDS interventions need to take into account communication contexts sensitive to conflicts in modern and traditional ways of life and contextual elements influencing behaviour in rural communities (Dalrymple, 1987). Rooted in participatory communication for social change theory, the project has a special interest in social theories and understanding the ways in which culture and education may act as a

⁸ Forum theatre involves the performance of an unfinished play to raise issues of importance within a community. The actors invite the audience to participate in proposing and challenging solutions to problems posed in the play (Seguin and Rancourt, 1996). The use of big screen technology combines the immediacy of drama with the accessibility of modern media and involves the audience in the games and activities usually used in the intimacy of a workshop context (Frizelle, 2003)

means of social reproduction of class, ethnic, racial and gender structures and therefore as a means of social control and oppression (Tomaselli, 1997).

Prompted by the recognition that there was a need for the capacity development of HIV/AIDS facilitators and educators, a peer training book was developed. This research process involved the development of workshops by young people affected by these issues (Sutherland 2002). This gender responsibility programme was evaluated by the Centre for AIDS Research Development and Evaluation (CADRE, 2001). The preliminary report findings suggest the workshop context created an environment in which equal partnerships between the participants were possible and that the context did not replicate socially repressive situations that may have existed outside the workshop (CADRE, 2001:8). The findings of this research indicated games and role plays in the workshop created consciousness and the ability to step outside of everyday lived reality and to reflect on it from a more objective and analytic standpoint. (Also see Mukoma, 2003; Frizelle, 2004, DramAidE, 2008).

The conceptual framework of the project was refined in partnership with CADRE. This was within the parameters of the national governments Beyond Awareness Campaign in higher education. This project was based on the understanding that people enact social roles and their attendant meanings are adopted from social conventions or established practices. It was for this reason that an activity and events based series of training workshops for staff and peer educators was initiated to develop a coordinated university response. Based on the conceptual framework described in *Communicating Beyond AIDS Awareness* (Parker et al., 1998) the project highlighted the central role of participatory communication in reforming and revising social norms. This campaign included the promotion of a social movement around the unifying symbol of the Red Ribbon in the development of media such as murals, plays, posters and dance which encourages the integration and representation of more meaningful and contextualised health messages rather than those developed by external experts for communities (Parker, 1997). The concept that communities are made up of activities that are communication-based and that these activities may be practiced, led to the development of the notion of communities of practice in health communication (Kelly et al., 2000).

Communicating Beyond AIDS Awareness was one of the first theory based HIV/AIDS campaigns in higher education that used a normative theory based approach that was

based on best practice and that was contextually specific (Swanepoel, 2005). Increasingly the project's focus worked to counter HIV stigma by developing a context that was supportive of people living openly with HIV. This led to the development of a project ensuring that HIV stigma was addressed on a legislative level in terms of higher education policy.

DramAidE evaluation (2001) found that HIV positive young people are well received by student peers and that opportunity for interaction has a positive impact on the attitudes of students in higher education (CADRE, 2001). External evaluations also found that the project had potential to initiate a social movement based on a positive approach to health that endorses the rights of people living with HIV (Frizelle, 2004). The Higher Education HIV/AIDS Programme (HEAIDS) rolled out a national project in 2004. This focused on the involvement of people living openly with HIV, who were encouraged to address campus community forms of stigma through informal contexts and peer to peer communication (DramAidE, 2008).

The project in the context of higher education

In the context of higher education, the HP project is DramAidE's largest programme with funding currently provided by the United States Agency for International Development through JHHESA (Johns Hopkins Health and Education South Africa). In 2006 the HP project was encouraged to make a major shift in terms of the project's prior dialogue-based strategy to mitigating HIV. From an ideological perspective dialogue is opposed to monologue or any didactic communication that reproduces dominant epistemologies which reinforce traditional power differentials in society (DramAidE, 2006/7; Kellner cited in Ed. Llan Gur-Ze'ez, 2003). The focus up until 2006 countered HIV stigma and critical gender issues, encouraging the practice of positive attitudes to people living with HIV and healthier lifestyles.

The resulting shift has seen a tension emerge between the original dialogic strategy of the project and a social marketing approach which promotes abstinence before marriage and counselling and testing (DramAidE 2002/3; DramAidE 2006/7; DramAidE, 2008). In the new approach the HP project has been challenged to market these messages to increasingly larger audiences. Amidst critiques of the ideological imperialism implicit in the abstinence till marriage, being faithful and 'other' prevention (otherwise referred to as 'risk reduction'), critics note the Presidents Emergency Programme for AIDS Relief (PEPFAR)

preferential funding towards abstinence-until-marriage programmes. These programmes are promoted over and above life skills and sexuality education interventions. Critics suggest that these programmes are problematically representative of conservative American values rather than being rooted in public health science. More recent critique suggests the behaviour change social marketing approach, which increases participation using 'entertainment education' formats, is being used as part of a moral ideological agenda (Epstein, 2007).

Mindful of the potential of 'participatory' programmes for ideological abuse there is an urgent need to critically evaluate the role of programme conceptual frameworks and whether they contribute to "freeing people and democratising society" or inversely questioning the potential of theoretical frameworks to develop programmes that "integrate(s) people into a hierarchy, transform them into consumers, accentuate social differences and becomes a useful instrument for ideological domination" (Dalrymple, 2004:1). Recent research suggests that DramAidE may have found a way to implement the abstinence-until-marriage approach using a problem posing centred approach. This approach advocates the representation of what people think and know. The idea that underpins the concept is that all people have unique skills and experiences that inform them how best to approach a problem. Problem posing involves people actively in identifying (from real life situations) where and how a problem is manifest. The process of involving them in a problem drawn from their lives ensures they are able to analytically and critically find the most appropriate way they can best deal with a problem (Singhal, 2003; Singhal, 2004; DramAidE, 2008). The approach is different from a problem solving approach in which a defined problem is identified and prescribed solutions to the problem proposed to a community.

LITERATURE REVIEW

There is little or no research on the HP project other than internal and external evaluations of the project (DramAidE, 2008). There is, however, an abundance of literature on other DramAidE project schools with detailed analysis of the theoretical frameworks that underpin the project (Dalrymple and Preston-Whyte, 1994). The evaluation and analytic work on DramAidE as well as theoretical work relevant to the work of the organisation are presented below. The review is structured according to key elements of DramAidE's

programme. An attempt is made through this to develop an appreciation of the implicit and explicit theoretical and empirical underpinnings of the project.

Behaviour change model

Most literature on the project has reviewed the project's efficacy in relation to behaviour change frameworks and more specifically as a social influence intervention in which social learning theory (Bandura, 1977; 1994) is a key component of the project (in Frizelle, 2004). Central to social learning theory is the perception that one is capable of performing or modelling behaviour (Frizelle, 2004). Citing behavioural models, these evaluations demonstrate that young people are more inclined (in the short term) to make better health and relationship choices (Sutherland, 2000; CADRE, 2001, Sutherland, 2002; Frizelle, 2003, DramAidE, 2008). Frizelle (2004) found that the young people who facilitate this project are often thought to model the ideal behaviours of people living openly and positively with HIV. They, however, also provide real examples of people who have had to negotiate the practical realities of living with HIV. This means that they can talk with insight about the difficulties of adjusting to a healthy lifestyle (Frizelle, 2004). They do this in an overtly non-political way by creating opportunities for face to face communication at exciting activities and events which because of the health promoter's charisma and the exciting repertoire of activities they create engage people in supporting the rights of people living with HIV and of other marginalised groups (DramAidE, 2006/7). It was also found that activities with HPs helped students to personalise the risk of HIV, demystify AIDS, break stigma and deal more effectively with health and relationship issues (Botha and Durden, 2004). An evaluation that built on this also found that the project built understandings of the social cultural factors that expose women to higher risk of HIV infection. It was also found that female students were more vocal on the issues of gender (Mukoma, 2003). Research in 2008 found that men in the project were just as vocal and expressed that they had been able to develop better communication skills and found that their relationships with the opposite gender improved as a result of the project (DramAidE, 2008).

Durden (2008), in review of the HP project (2008), highlights that Entertainment Education and Peer education are core components of the methodology which are found to be popular. Entertainment education is found to be interesting and innovative for students. The strength of peer education is that it enables students to spend time together working

over their attitudes, beliefs and working skills (Duetsch et al., 2003). It is limited in that it only reaches a small minority of learners eager for health education.

In DramAidE research and HP project evaluations, entertainment education and the performing arts are cited as modalities that bring about “change” (Sutherland, 2002; Frizelle, 2004). The entertainment education model uses educational and entertaining formats to create favourable attitudes towards desired behaviour. It involves the careful design and implementation of messages to show individuals how they can live safer, healthier and happier lives (Singhal and Rogers, 1999). Research findings support its effectiveness for HIV/AIDS communication and empowerment of marginalized people (Nariman; Piotrow et al., 1997 cited by Cholmondeley, 1998). Entertainment education is particularly relevant for use as a catalyst for human development and empowerment which is particularly relevant for SA higher education institutions in which stigma is still prevalent despite opportunities for anti-retroviral therapy (Cholmondeley, 1998; Chetty, 2000; Epstein 2007). Analysis, however, is largely underpinned by behaviour change (BC) models and does not sufficiently consider the role of Freireian method and Boalian dramaturgy in revising identity.

A key criticism of the behaviour change model is that it is based on the assumed ability of individuals to assess, think critically and make reasonable decisions in a context where the extended family and community influence the decision making of the individual (Airhihenbuwa and DeWitt Webster, 2004) The strong influence of community determined norms makes it difficult to practice habitual safer sex within the perceived parameters of predefined ‘risk’ reduction interventions (Hamilton et al., 2007). Research suggests that the system for communicating risk – its people, rules, formats, and technologies – is a part of its social meaning. These heuristics are at times manipulated in ideological ways to create artificial dichotomies which include public/private, winners/losers and scientists/people and that across a variety of social contexts it is at times manipulated in ideological ways.

The behaviour change model also does not sufficiently take into consideration that change is contingent on particular pre-conditions or predispositions being fulfilled (Kelly and Parker, 2000). Behaviour change models have been critiqued for assuming that risk protection is a priority in resource constrained settings and that there is the motivation to comply with externally prescribed behaviours. There is also the assumption that

communities do not have their own ways of managing risk. Furthermore, they assume that decision making is volitional and not socio-culturally mediated. In other words, models emphasise 'agentic rationality' (individuals as rational agencies making decisions about their own behaviour prior to committing themselves to action) and is devoid of understanding "the challenges of lived experience "(Kelly and Parker, 2000) where behaviour as much 'happens' to people as it is chosen. It is therefore argued, that there is a need for community approaches which can revise social norms and develop solidarity to address issues of intentionality (how people are committed to action) and to revise harmful social practices and mediators of behaviour (see Campbell, 2003; Shisana, 2002; Swanepoel, 2005).

Communication for social change theory has developed in resistance to bio-medical HIV/AIDS communication and is influenced by converging trends in social change theory and developments in health promotion and health communication (Moodley, 2007). More recently there has been a shift towards more community mobilised approaches to HIV/AIDS in which there is greater emphasis on community mechanisms for developing private and public dialogue and debate to revise social norms and cultural values in a supportive community context (Scheepers et al., 2004)

Community based approaches

In literature on community change the project falls outside of the ambit of traditional health promotion projects which usually advocate lifestyle changes. This project is on the other hand concerned with building on and encouraging behaviours that are already working well within a community (Kelly et al., 2000). This approach to health promotion focuses on what positive attributes in a community can be maximised to their full potential to create learning opportunities. This approach seeks to revise outdated norms, to develop a mindset that recognises good health and wellness, rather than a focusing on aspects of the disease which are not life empowering (see Antonovsky, 1996).

Campbell and MacPhail (2002:2) highlight the value of social and community contexts that "supports the renegotiation of social identities and the development of empowerment and critical consciousness". Ideally, they emphasise that it involves a process in which group norms are formed as the result of a process of collective negotiation by young people in group settings. Peer education in the context of a health promoting project, typically involves a process of co-operation, trust and a positive, reciprocal community identity.

DramAidE's empowerment model works on a collective level "to empower the community through developing self-reliance in all aspects of life" (Young, 1997:24). This is accomplished by the transference of knowledge, skills and resources that enable individuals to take action and responsibility, and remove obstacles that may have, in the past, hampered this (Durden, 2003). This process hinges on a participatory approach which essentially encourages the development of "a thinking society" in which issues are argued, debated and negotiated within an evolving group process (Campbell and MacPhail, 2002:3). Campbell and MacPhail note that in theory participatory approaches should provide contexts in which young people can generate their 'own indigenous critical analyses' and reach their 'own self-generated solutions' on the basis of such critical analyses (2002:5). HIV/AIDS interventions need to challenge peer-education programmes to be non-prescriptive, critical of messages and formats. That is if they are to address the complex ways in which HIV/AIDS is manifest in people's lives.

Development and empowerment

Empowerment is a 'social action process by which individuals, communities, and organizations gain mastery over their lives in the context of changing their social and political environment to improve equity and quality of life' (Wallerstein and Duran, 2003). A critical element of empowerment theory for health educators is the participatory process in which people might engage to improve quality of life. As an exemplification of participatory processes, 'social capital' is an emerging construct that links community participation with notions of trust, shared emotional commitment and reciprocity (Peterson and Hughey, 2004). Social capital refers to an approach which recognises that when people feel that their needs, views and opinions are respected they are more likely to participate in social networks and organisations. An increase in participation in community structures has been shown to enable people to individually and collectively respond to social issues and develop a positive community identity (Campbell and MacPhail, 2002). Collective action has been linked to the development of a 'health enabling' context in which people identify with a positive social identity. This often leads to improved sexual health and increases in the confidence by marginalised people to address factors that fuel inequality (Hemer, and Tufte, 2005).

Social capital, development and empowerment are integrally intertwined concepts (Kelly and van der Riet, 2000). In this analysis social change cannot be divorced from concepts

of development nor empowerment. Ideological shifts are implied in the changing relationship between those who have been historically dominant and those who have been marginalised from power (Kelly and van der Riet citing Freire, 2000).

The project draws on participatory development for social change principles which communication which has come to be regarded as a normative theory of participation (Servaes, 1995). The Freireian model is characterised by a principle of respect for the humanness of others. This implies dialogical communication and action which can only take place when those who historically have been subjugated reclaim their right to speak out and prevent dehumanising processes such as discrimination (Servaes, 1995:78). This is achieved through a method of deepening consciousness in which action is reflected on through the dialectic of action and reflection moving to consciousness.

The HP project is people centred and gives voice to those who are most affected by HIV. People living with HIV are seen as the nucleus of development and social change in the project (see Parker, 1997; Nduhura, 2004). It is for this reason that the Health promoters facilitate the project with the cooperation of the university community. That enables the development of relationship with student bodies, academic staff and management (Kelly, 2001). This resonates with DramAidE's commitment to encouraging the project to develop motivated by people in the community rather than being initiated and controlled by the programme (Dalrymple, 2004). In order to ensure that the Health promoters are easily identifiable with, representative of students and familiar with local culture the institution encourages peers drawn from their community to openly live with HIV. It is through this process of inspirational leadership that the Health promoters create opportunities for dialogue on issues relating to living openly with HIV and to address complex social structures underpinned by gender stereotypes. In this way local community can engage in dialogue and strengthen democratic processes and institutions. This includes the development of HIV/AIDS policy and the integration of openly positive people into employment structures. Earlier models of development are critiqued below in terms of Freireian principles of development.

Development model critique

Modernisation as a development approach involves the extension of technologies and resources to passive recipients (Kelly and van der Riet, 2001). Freire's *Pedagogy of the Oppressed* (1970) was written in response to what he termed the culture of silence that

pervades the developing world. Freire argues that 'Technocrats' perpetuate cycles of passivity and dependency (Melkote and Steves, 2001; Singhal, 2003). Communities such as these are often characterised as apathetic and suffering from fatalism (Freire cited in Kelly, 2000). Modernisation results in cultural alienation and is accompanied by political alienation as people adapt to the dominant value system. Freire (1972a) considers the oppressed, as people who are marginalised by perceptions that label them as deviant and different from "good organised and just' society". The trauma of cultural "loss" corresponds to what Freire terms "magical consciousness" characterised by a passive-defensive response (Tomaselli, 2001; Smith, 2002).

Dependency has led to paternalistic perceptions of the developing world as ignorant and backwards (Freire, 1972a). Freire (1972a) argues that dependency is a result of the maintenance of a communication relation by the dominant social group through the structural control of knowledge. This instils in the poor and marginalised a self-perception of lower status characterised by social, political and cultural incompetence (Cornwall and Jewkes, 1995). Traditional education is privileged over and above local culture. This denigrates and devalues local culture (Smith, 2002). "Naive consciousness" or an awareness of the problem may be realised; however, this often does not lead to recognition that structural components perpetuate the status quo (Campbell and MacPhail, 2002).

Increasingly people-centred approaches to participatory development are touted as an appropriate philosophy for society to increase personal and institutional capacities to mobilise resources (Kelly and van der Riet, 2000). Development support communication emphasises the participation of the beneficiaries in the conception and development of strategies. This approach is critiqued, however, for often being undermined by a Eurocentric top down "banking" mode (Freire, 1972a). Freire (1972a) considers this representative of a style of pedagogy in which a teacher is the repository of knowledge and the student is the passive learner (Smith, 2002). In this development paradigm, problems and solutions are often predefined, followed by consultation with beneficiaries which serve to persuade and endorsement of the process (Odei Ajei, 2007). Therefore by bringing in outsiders to organise, one would decide *a priori* a conceptual direction and concomitant practice.

Historically, in the context of the 'imperatives' of the HIV/AIDS epidemic to 'save lives', a rapid response has often been justified (Parker, 2004). In critique of the moral panic ascribed to rapid health crises responses, researchers suggest that a "morality of compliance" is the consequence rather than addressing public health (Nord, 2001). Dalrymple (2004) therefore argues, "Health promotion is best produced by the community itself and should not be a gift from the elite to the masses" (Dalrymple, 2004). The rationale behind this is that if approaches to development or education are implemented in a top-down approach then the future will be anything for the oppressed but a continuation of the present. "Authentic education is not carried on by 'A' for 'B' or by 'A' about 'B,' but by 'A' with 'B'..."(Freire, 1972a).

Alternative development furthers an approach in which the community members become agents of change rather than being led by outside agents (Servaes, 1995). This is an eminently political act that enables people to draw on their own expertise, become aware of themselves, and of their potential to act on their environment (Smith, 2002). This alternative approach to development is also sometimes called a resistance approach (Mwasaru, 2007). This is particularly apt when one considers the nature of the HP project and that participatory action research that underpins it. The participatory action research approach was used as it contains many of the development principles outlined above. Paulo Freire's method of 'problematising' is a key factor in assisting people to recognise that there are alternative ways of doing things. The method is useful in stimulating research that is relevant to a community and not necessarily defined within the prescribed boundaries delineated by the researcher.

Freireian pedagogy

There have been several DramAidE studies which have examined the use of Freireian pedagogy to bring about change with specific reference to gender and HIV (Kelly, 1996; Young, 1997; Nduhura, 2004). In national and international studies, Singhal (2003; 2004) has developed DramAidE case studies which analyse the role of Freireian pedagogy in peer education contexts and the use of participatory theatre or social change.

Freireian method is a conscientisation process which enables the analysis of ideologies, power relationships and their underlying values. This is of importance as it situates all human action within historical context and as culturally encoded as a part of ideology (Fontdevila, 2006). The usefulness of Freireian method by DramAidE in revising identity is

supported by pilot study findings. Sutherland (see CADRE, 2001:7) in evaluating the piloting of a series of workshops for the youth from NGO's notes the efficacy of the project in developing understandings of "power relations, culture, identity traditions and their interrelatedness with gender". Frizelle (2004) similarly highlights the efficacy of games and interactive entertainment to deconstruct social, cultural and political factors which influence the realities of HIV/AIDS. She also points to the ability of the performing arts to stimulate open dialogue and create awareness. This resonates with Freire's contention that central to developing consciousness of the world is the need to question *a priori* understandings of the world in which we live (Freire, 1972a).

Freire's method of problematising first involves debate and critical reflection which exemplifies a more democratic form of knowledge production in which people are involved in their own education (von Kotze, 2005). More recent evaluations suggest that there has been some success in the project influencing young men and women to engage in HIV related activities that create openings for the renegotiation of communication spaces about gender (Frizelle, 2004). A significant finding of this research positions the project as a social movement in which young people provide inspirational leadership to develop confidence and self efficacy in their ability to make better lifestyle choices and build healthy relationships. The significance of this in terms of initiating social change suggests that young people have been able to revise stereotypical attitudes about people living with HIV and work together to create a supportive community environment. These findings suggest that counter-hegemonic critique is developing through actions that involve young people as subjects who address the dehumanising effects of HIV stigma and harmful gender practices (Freire, 1972a).

Conscientization refers to the attempt through education to enable progress from a stage of submerged consciousness to a state of critical consciousness (Freire, 1972a). Sutherland's analysis of the workshop method points to this conscientization process. 'Training on patriarchy' is theorised in terms of creating "consciousness to step out of (oneself) to create new patterns, developing realisations that familiar games (when viewed objectively) open up new possibilities". Further research on the project by Mukoma (2003) suggests that the strength of DramAidE's approach lies in its "critical dialogical ...ability to deconstruct *apriori* epistemology" (Freire 1972a). Findings suggests that students use a

process of action and reflection to develop understandings of the issues that place people at risk from gender issues that impact on prevention (Mukoma, 2003).

Freire (1972a) suggests that the challenge for education is to shift people's self perception so that they see themselves as makers of culture rather than as passive recipients thereof. This shift can be perceived in Mukoma's (2003) findings which indicate that the project opens up spaces for the creation of a culture of living positively with HIV. This space not only allows for a shift away from discriminatory practices, it also engages young men and women in creating a communication context in which they can more easily participate in prevention. This is not only especially significant for women who usually find that HIV stigma prevents them from disclosing and seeking treatment but also for men who need coaxing to participate more enthusiastically in dialogue on gender and HIV/AIDS (Mukoma, 2003).

Freire's notion of empowerment encourages a more cognitive understanding of social problems that need addressing and encourages intellectual analysis (Dalrymple, 1987). Empowerment is usually conceptualised in terms of a subjective sense of confidence and ability to act (agency), within given socio-cultural and economic structural constraints (Campbell and Macphail, 2002). This critical pre-condition for the development is that beginning of a heuristic group process in which deductive thinking through experiential practice challenges 'being victims of our own biography' (Dalrymple, 1987). This is of significant relevance in using Freire's method to cope and counter HIV stigma.

Cultural theatre pedagogy

Critics of Freireian pedagogy find that the methods that are used for social change focus on abstractions of power and oppression. In other words, this transformational approach places emphasis on exposing the embedded *a priori* understandings of the problem and exposing the reification of cultural epistemology (Kelly, 2000). In other words, it is able to address larger social problems but does not inform the actions that can challenge structural oppression in the lived experience of day to day life. In acknowledging the limitations of Freireian theory to address activity based change, it is still useful to apply the conceptual framework that informs this theory in another way.

Augusto Boal's (1979) *Theatre of the Oppressed* (TO) is inspired by and draws on Freire's *Pedagogy of the Oppressed*. Oppression, Boal argues is experienced not just intellectually

but also physically and emotionally. So the struggle to overcome oppression must necessarily involve an engagement with the physical and the embodied TO involves activities that address the embodiment of oppression through a focus on image and sound. To this end, Boal turns theatrical convention on its head and recruits 'spectators' as 'spectactors'. 'Spectactors' take the place of the actor who is playing the oppressed individual, and attempt to present a different resolution to the enacted situation. In this way, multiple means of overturning oppressions and working through social dilemmas are explored. .⁹ The process is meant to create a context in which opposing arguments can be considered rather than ignored.

The relevance of this method in the African context is its ability to deconstruct the 'performance' of everyday reality and how it is mediated by socio-cultural and economic factors. This is especially useful given that Africa has its own tradition of group communication for freedom expressed in popular theatre and other typically African forms of participatory group communication. These include dance, song and community rituals (White, 2008; Preston-Whyte, 2003). Drama has been a popular medium used in sub-Saharan to further development and health goals. This is often because it is able to use local languages, cultural formats and overcome the barriers of illiteracy (Mda, 1993). Ross Kidd's (1982) work in theatre for development and interactive entertainment has played utilised the Freireian and Boalian methods as tools to develop social consciousness. The medium is ideal for education that is simultaneously an act of knowing, a political act, and an artistic event (Freire quoted in Giroux and McLaren, 1997).

Boal argues for an aesthetic sensibility which refers to the awareness that "we cannot divorce reason and feeling, idea and form" (Boal, 2006:15). This approach highlights a mode of engagement that involves using drama for relearning entrenched social narratives. Because drama uses games, songs and role plays (and is similar to the way that we learn as children) it can be considered a natural way of learning (Boal, 2006).

⁹ Boal's theory and methodology has resonance with Pierre Bourdieu's (1990) 'habitus', which refers to embodied systems that are reflective of our individual and collective histories and the structures in which we are embedded. We may not normally be aware of habitus, but Bourdieu argues that we can become aware of it through conscious reflection. Unconscious, normalized, and embodied oppressions are at the root of social reproduction of inequalities, such as those based on race, class, and gender. By exposing the habitus of our being and attempting to transgress it when needed, Boal aims to stop the cycle of social reproduction.

Through becoming characters and engaging in narrative, children learn about structures of society and the rules of their community. In the same way drama uses culturally resonant modalities to expose culture, deconstruct cultural rites and to reconstruct rituals and social conventions in positive ways (Singhal, 2003). TO uses games and role plays as tools to investigate everyday narratives and also to 'rehearse' new narratives (Dalrymple, 1997). This analysis works on a deeper level than just the cognitive and uses both reason and emotion. It also involves rational judgments and values and uses both the body and the mind.

An aesthetic awareness encourages reflection on both the content and form of communication modalities. In practice this means that analysis of the form of communication and the way that it is structured enables the disclosure of oppressive narratives that are often hidden and unexposed. These hidden narratives can exercise tremendous power over individuals since they are often regarded as commonsensical and factual rather than as worthy of being contested, questioned, or examined. Boal therefore argues that TO can be used to expose the hidden or underlying narratives that lie at the centre of our meaning-making process and are often sources of oppression for those who stand in the margins of society. Boal claims that TO goes beyond merely revealing these narratives. Furthermore, TO treats these narratives as in a metaphorical way which opens up a space in which multiple interpretations and competing counter narratives can be considered.

RESEARCH OBJECTIVES AND QUESTIONS

In the application of Freireian pedagogy to this case study the intention is to examine the theoretical and conceptual frameworks that are used in the HP project, that lend themselves to the reconfiguration of harmful patriarchal practices.

There are two objectives of this research. The first objective is to improve understanding of how a community creates a revised vision of male/female gender communication and by doing so address HIV stigma. The second objective is to develop a deeper understanding of how young men and women are able to address a context of HIV risk so that it enables a supportive environment people living with HIV.

Specific research questions

- 1) How do young people living with HIV experience prevention in the context of a higher education context?
- 2) Is the application of Freireian pedagogy a sufficient enough construct to revise of social norms to mitigate HIV/AIDS?
- 3) How do young people living with HIV cope and counter HIV related stigma and gender discrimination?
- 4) What is the significance of this project in addressing HIV stigma and its implications for increasing access to treatment, care and support in higher education?

CHAPTER SUMMARY

This chapter describes a community based social change project that utilises the expertise of local people who are familiar with the socio-cultural context in which sexual practices take place. An argument is made for the need to recognise that when social norms are strongly supported it is easier for a person to act consistently with social norms. An example is made of the HP project literature to highlight the value of the need to understand the processes of change that this research study explores. This is discussed in relation to Freireian pedagogy and argument is made for the need for communities to investigate *a priori* concepts and epistemological practice.

CHAPTER 3 – RESEARCH METHODOLOGY

OVERVIEW

This exploratory study is rooted in a broad participatory action research framework and as such the relationship of the researcher to the research subjects is an important consideration in detailing the ethos in which the research takes place. In consideration of the culture of the HP project a description of the context in which this case study takes place is important in contextualising the case study.

In broad terms this research approach views the context through a lens that resonates well with Freire's (1972a) view that reality is not ahistorical or acontextual but rather that all perceptions and experiences must be understood as a specific reading at a particular place and time. This recognition is negotiated by a meaning-making process of the specific communicative context. The purpose of the following research processes is to develop a context specific understanding which explores the communicative contexts and their meanings of the HP project. Gergen (1997:57) refers to this process as, "the specific modes of life, rituals of exchange, relations of control and domination". For the purposes of this chapter these processes are divided into three parts with the intention of developing:

- 1) Contextualised understanding of the project through a review of its literature
- 2) Understanding of the meaning making process through a participatory workshop
- 3) Deepening understanding through focus group discussion with peer educators and support group members.

The researcher has worked with the HP project at Durban University of Technology over a seven year project as a staff member of DramAidE since the inception of the project in 2001. This has involved developing a long term relationship with the staff, students and Health promoters who have been a part of this project over the years. This relationship has been characterised by honesty, trust and mutual respect and has been a mutually enriching experience (FGD, 2007). Over the past several years the relationship has deepened with social contact still maintained between those who graduate from the institution and the researcher. This long term association with the people of the project has seen the project grow. Over the years there have been celebrations and sadness, memorial ceremonies for those who had passed away, graduation ceremonies and celebration for those peer educators who have found work related to their activities in the

HP project. The HPs who are currently employed by the university to facilitate the HIV/AIDS programme have been peer educators and support group members and have been with the project since its early days. Many of the community members who are still involved with the HP project have been students who participated in the project and who now in their professional capacity mentor newer members.

ETHICS PROCEDURE

Research needs to be coherent and compelling to the same degree that it is moral and ethical (Mason, 2002:4). It was with this in mind that the research process was designed to ensure that critical and ethical considerations should shape the study so that no harm should come to the study participants. This first consideration was defined by the likelihood that the subjects of the study might have suffered HIV related trauma and could be affected with someone close or themselves living with HIV. This was likely given that the location of the study site at the confluence of an urban transport site in KwaZulu Natal where the infection rates are regarded as the highest nationally (Human Sciences Research Council, 2008). With this in mind the research process needed to be sensitive to the levels of distress and trauma involved in sharing experiences. White finds that it is desirable for people to find their own way of giving voice to their experiences in ways that are profoundly healing for them (1995:87). He also encourages people to define the parameters in which the reinterpretation and expression of their lives takes place. This involves people checking with each other how they are experiencing processes and encouraging them to take responsibility for their own level of emotional comfort.

A key consideration for the researcher, given the application of Freireian methods, was to recognise oneself as potentially influential in the structured learning environment whilst taking care to maintain the dialogical nature of the conversation. This meant that it was important to view the participants as experts in their own lives, with their own knowledge (Freire, 1972a). The research approach embraces principles of participation and reflection. It also suggests a communicative context in which people interact as co-participants in a community (Kemmis and McTaggart, 2005:563).

For the purposes of this study the term community refers to the people who are in some way involved in the HP project. In other words community is defined by a group who share a common interest and who form part of a communication network that consider gender and HIV stigma important issues. An ideal horizontal communicative relationship is,

however, difficult to achieve within the reality of a socio-cultural context where different role players wield different types of power (DramAidE, 2008). MacTaggart (1997:33) warns that even though one might develop a sense of community solidarity within the group the researcher needs to be mindful of the subtleties attached to the role of the academic role in facilitating the study.

The context of this study provides several research opportunities. Although this was ideal for the purposes of the research, it also raises some concerns with regards as to who benefits from the research. Firstly the site provides access to participants who are open about how HIV affects them, willing to discuss gender issues and who are involved in prevention and care initiatives. Secondly, a recent advance in the project has led to the development of a support group which is of value, given the interest of the present study on how masculinities, HIV stigma and prevention interface. Thirdly, the site also provides the opportunity to study a disclosure project in which HIV positive people are actively involved in counselling and testing.

As much as the intent of the research is to investigate how young people are able to revise traditional notions of gender and revise HIV stigma in their everyday lives, the participatory action research approach chosen for the study was found to provide an opportunity for the voices of people living with HIV to be heard about their role in care and prevention. A research concern was that management was not more involved in the research process and there was the danger that management issues could be misrepresented or not seen in context resulting in the realisation of plans without a negotiated framework in place (see MacTaggart, 1997:4). This concern was kept in mind given the sensitive nature of the research.

It was for this reason that:

- 1) Permission to conduct the study at the location was negotiated on several levels. This involved the drafting of a letter for Durban University of Technology (DUT). This letter indicated that the ethics of the project had been approved by the ethics committee at the University of KwaZulu Natal and detailed some of benefits of the study for the HIV/AIDS programme. Some of these benefits included adding to knowledge about the project and potentially informing future developments.

2) The study parameters were clearly defined and it was ensured that no harm would come to the participants. This meant ensuring that the study design would be assessed throughout to ensure that all practices were construed to develop resilience and improve the subject's self confidence and efficacy. This was especially important as the study process developed and it emerged that all the participants were living with HIV and were most likely to have unresolved issues that might come to the fore during the study.

3) Trained professionals would be available for trauma counselling in the event of any trauma being triggered. It was negotiated that trained counsellors who are living openly with HIV and work on the campus participate in all sessions. Student services were contacted prior to the research to ensure that appropriate support or referral would be available if required. The availability of Voluntary Counselling and Testing services at the HIV/AIDS unit was negotiated prior to the research beginning on the campus.

RESEARCH APPROACH

Underlying the concept of disease stigma is the idea that both people and society construct their own realities. These are shaped to some degree by socio-cultural processes (Deacon et al., 2005:9). Social constructionism focuses on understanding how people make sense of their experience and on exploring the meaning constructed from this. It is with this understanding that the social construction of identity can be therapeutic if attention is paid to understanding the context in which the research is undertaken (Mason, 2002). This understanding guides the current research approach and careful consideration is given to the intimate relationship between the researcher, subjects of research and the situational context that shapes enquiry (Denzin and Lincoln, 1994:4). The communicative context is of importance as identity is constructed. As Stein et al. (2003) suggests, "when people's shared discourses seep into our constructions of self...the experience of living with HIV/AIDS cannot be separated out from the social construction of HIV/AIDS as a stigmatised disease (Stein et al., 2003:4 citing Peterson and Benishek, 2001; Sontag, 1991).

Action research sets out with a specific aim to address a specific problem in a specific setting using precise knowledge, and is often driven by a predetermined research agenda (Banister et al., 1994). McTaggart (1997) further elucidates that the difference between participatory action research and action research is that the latter is usually employed by the researcher with the aim of improving practice. Participatory action research, however,

is often more orientated towards helping a group to identify and act on social policies and practices that keep unequal power relationships in place. Participatory action research has therefore historically drawn attention for greater consideration of the ethical and moral implications of research. McTaggart (1997) highlights that participatory action research by definition emphasises that participants collaborate in 'co-research' to 'co-create their lives'. 'Action' highlights and emphasises that it is the participant's own actions that are meant to be informed by the research project, and not the future aims of the researcher. McTaggart (1997) accentuates that to this extent research is engaged in by people in pursuit of their own interests. Participatory action research is therefore of value in research such as this where there is concern with equity, self-reliance, and oppression problems. Given the political nature of HIV, participatory action research is about people changing themselves and their circumstances and informing this change as it happens (van der Vliet, 1996). This approach uses an active whilst reflective process which encourages the development of a 'collective critique' which is overtly political in nature. It sometimes assumes that the research may be resisted by those with powerful vested interests (McTaggart, 1997).

Although the research approach suggests a communicative context in which people interact as 'co-participants' in a community by the very definition of researcher and research subject, a power differential exists between those who study and those who are studied (Kemmis and McTaggart, 2005:563). A challenge for the qualitative researcher is where they are situated on the level of outsider and the degree to which they are accepted as insider.

Freire (1972a) addresses the power contradictions inherent in this relationship by suggesting that dialogue should be both a process of action and a goal to aspire to. Thus the linking of ideas with particular actions would ideally be informed by the notion of praxis. Praxis has come to refer to action which rises out of and contributes to critical reflection. This presupposes that certain actions are driven by particular ideas. It is in analysis of the action and the ideas informing them that change happens. Analysis suggests a deepening of understanding to inform action. In the analysis of issues the purpose of the participatory action research process is designed with a view to identifying ways and means to further the aims of social justice.

This dialogical process is envisaged as a transformative empowerment process that has the potential to challenge the dialectical relationship between the 'oppressed' and the

'oppressors'. Kelly (1999) points out the complex relationship in representing the research subject's voice and how the researcher needs to be critical in order to move the research subject beyond the limitations of his/her own cognition of their context. This encourages a deeper reflexive understanding of the researcher's relationship with the participants. The quality of the relationship between the researcher and subjects is an integral part of the participatory action research process, in which communication is both a dynamic and reciprocal "transaction" in which negotiated meaning is exchanged. Kelly and van der Riet further suggest that Habermas's concept of communicative action (1972) is useful to address the limitations of the researcher in bridging the gap between researcher and research subject (2000:24). Communicative action, in this context, describes the deliberate intention to encourage the free exchange of beliefs and intentions without domination (Habermas, 1984). This reciprocal relationship underscores this research process and also provides a framework in which feedback is associated with the recognition that mutual understanding is the goal of communicative actions. Habermas's theory resonates well with Freire's belief that all people have the ability to bring about that understanding through our basic relations with others. This directs our attention to the nature of the relationship between the facilitator, animator and participants. The role of the facilitator is to create a structured environment in which each person becomes both teacher and learner and the subject of their own learning. It is for this reason that the intentions or motives of the researcher are critical in developing a more democratic or dialogical communicative process.

STRENGTHS AND LIMITATIONS

In participatory research people make decisions about the study format and data analysis (Reinharz, 1992). In the design of the research approach the participants were consulted and a workshop process was agreed on. It must be noted that a limitation of the research approach was that the action plan was defined by the researcher. The use of Freireian methods, however, did accommodate small changes to this process. The process remained somewhat flexible and responsive to the needs of the participants. As the group of participants consisted of a mix of several African cultures, languages and religions consideration of the researcher's limitations in selecting, interpreting and analysing data is important.

RESEARCH METHODS AND PROCESS

Qualitative research is often spoken of about as ‘theory generating’ (Kelly and van der Riet, 2000:8). A theory building approach to this exploratory case study is used. This method begins with a specific proposition and then explores how and if it works within a specific setting. The purpose of the exploration of the proposition is to refine the application of a specific theory and to enrich the case study context (de Vaus, 2001).

The research was divided into three components that are typical of research processes. This involved:

- 1.) Use of an exploratory discussion to establish a focus for the research and also to establish a research process that was sensitive to the participant’s needs
- 2.) A participatory workshop with support group members to act as a catalyst for discussion
- 3.) Focus group discussions with the support group to interrogate themes from the workshop.

1.) Exploratory focus group discussion with peer educators

During 2007 focus group discussions and interviews were conducted at Durban University of Technology (Steve Biko campus) as part of a national case study conducted for the DramAidE project evaluation (2008). This evaluation served as exploratory work for the current study. The DramAidE study included various methodologies for collecting data. The main methodology employed was a focus group discussion with peer educators who were members of the HP project. The questions for the focus group discussion were designed by the current researcher.

The discussion was conducted with peer educators at the Durban University of Technology campus. For the purposes of this study the term ‘peer educator’ is used to describe young people who facilitate a wide range of activities such as group presentations, social marketing of condoms, distribution of materials and running support groups, drama groups and social events as well as one-on-one discussions with their peers (DramAidE, 2008).

Nine participants attended the discussion. The gender composition of the group was approximately equal (male – 5; female – 5) and all the students were aged between 18 and 25. The majority of the students were in their second and third years of study. All of them had tested for HIV. The specific focus of the exploratory focus group was to explore peer educator's experience of the HP project. The specific intent of the discussion was to assess the value of the HP project and its methodology. The purpose of inquiry into the project's methodology was to identify what the participant's found to be most effective about the project.

Participants and recruitment for the study

The first point of contact was with a senior member of management who advised as to whether access to the campus and the students would be granted. Recruitment of the discussants for the peer education group of the current study was initiated with an informal meeting with the HP and the HIV/AIDS unit supervisor. The HP arranged a meeting between the peer educators and the researcher. At this meeting the study protocol was outlined with twenty peer educators. Points of clarity were discussed and the voluntary nature of study highlighted. A list of respondents interested in participating in the study was compiled.

The selection criteria specified that respondents should be self selected, have an interest in the subject matter and feel that they should be able to contribute to the study. No incentives were used to encourage participation. English was specified as the main language of discussion, given that this is the main language of tuition in higher education.

The HPs played an organisational and mediating role with students and management. This meant that they informed students and management about the research project. They facilitated access to the students, provided them with information and liaised with management and myself.

An appointment for this exploratory session was made with twenty peer educators. A member of the peer education group agreed to be the key contact member in the group and to liaise between the HP, researcher and the peer members. It was felt that this procedure would relieve the participants from any undue pressure to participate. Five peer educators withdrew from the study citing exam pressures as the cause. Fifteen participants chose to participate in the study.

Procedure

A meeting was held in the board room at the counselling centre where the HIV/AIDS unit is housed. This part of the study was conducted over a weekend. This ensured the privacy of the discussants and that disturbances would be minimal. Students noted that they felt comfortable using this venue because the venue was familiar to them. Privacy ensured that their anonymity and confidentiality would be ensured.

Prior to beginning, the research protocol was read aloud to the participants and the conditions of discussant participation discussed. The group members were requested to use first names only and were briefed on the need for confidentiality. Consent forms were read aloud and clarificatory questions responded to. These were later signed, collected and stored with the data. The focus group lasted for an hour and a half with discussion running over the allotted period while students had tea.

The nature of focus group discussion is that it encourages people to draw on their own experiences. The technique uses inductive questions which encourages people to share their opinions and experiences. The facilitator's role was essentially a management role to ensure that the process and purpose of the research was aligned with both the needs of the research and the needs of the participants (Buskens, 2003). The assumption of the facilitator's role was qualified by the recognition of the reflexive and transactional nature of the communication process (Kauffmann cited in Kelly, 1997).

The researcher/facilitator role in the workshop was qualified by an attitude that avoided sympathy with any victim-based group narratives. The focus group discussion used open ended questions to elicit recollections and to guide reflection by peer educators on 1) the goals and methods employed by the HP project in revising stigma and gender norms, and 2) experiences of HIV and gender prejudice and ways that these are addressed to increase access to counselling and testing, treatment, care and support.

Data capture

It was agreed that all study processes would be recorded and that the material would be transcribed by the researcher who would assure the anonymity of the discussants. It is acknowledged that it would have been ideal to have a co-facilitator to assist. Members of the peer group, however, insisted that they were more than able to assist if there were any

difficulties. They would assist by monitoring the recording devices and by making notes of issues that they would like to discuss more deeply.

Data collection process

The researcher ensured that all the respondents were present and filled in a register detailing gender, age, contact details and student numbers. The time period of the data collection process during the focus group discussion was set at ninety minutes. Transcripts of the focus group discussions were made from the audio digital recording. All data was stored by the researcher in a secure environment, with the only access to the research allowed by DramAidE. This was negotiated with discussants prior to the workshop.

2.) Participatory action research workshop

Discussing how HIV affects one's life is a personal subject and dealing honestly with this involves overcoming taboos and prejudices. It involves giving or restoring to people simple and useful ways of understanding their bodies, their health and their emotions (Seguin and Rancourt, 1996:64). It was for this reason that the workshop drew on both Freireian and Boalian methods to engage people intellectually, emotionally and physically in exploring how oppression is embodied.

Freire argues (1972a) that the purpose of education is that people should be the subject of their own learning and so that they can be the authors of their own liberation. This involved creating generative themes or codes in which a community co-participate in using their own expertise in order to create a structural dialogue in which everyone participates in creating a picture of their social context. The workshop's first objective was to create a comfortable space for a dialogue to take place in and to promote the experiences of the research subjects. An environment conducive to creative problem posing begins by establishing a relationship of trust so that participants can honestly begin to engage critically with their problems. A problem posing approach involves reflection on activities that are drawn from the experience of the group and has the potential to inform future actions and promote individual and social change (Freire, 1972a).

Freire's notion of cultural action (Freire 1972b) was important in consideration of appropriate and relevant exercises and songs that would be used to trigger involvement so that people would actively produce their own knowledge and culture. It was important that people experienced the activities on physical, emotional and intellectual levels and so

physical constructions of everyday life were made using body sculptures. This was a useful way to start unpacking the issues that we experience which contribute to social problems. Creating images of life began a process reinterpreting the meanings of lived reality and finding alternative ways of thinking and acting (Lesko, 2005). The use of interpretive art forms develops not only cognitive awareness; it also stimulates a response that is contextualised and relevant. As Freire describes it: "the process in which people, not as recipients, but as knowing subjects, achieve a deepening awareness both of the socio-historical reality that shapes their lives and of their capacity to transform that reality"(see Carr and Kemmis cited by Parker, 1997:65).

The workshop drew on several conventions that occur in everyday life and ensured that rituals of greeting, getting to know people and socialising in an informal way set the casual tone of the workshop. This ensured that a participatory process in which people were comfortable and relaxed was established. The organic and fluid social process was also structured by conventions that the participants are familiar with. Familiar popular and traditional dance and songs were used as a means to initiate analysis of social norms. Beginning with what people 'know' was found to deepen their commitment to starting analysis of social problems as these 'issues' were drawn from their everyday lives.

The process orientated approach used various codes which were used to explore issues in an in-depth way and from different perspectives. Two codes were developed which were an amalgam of stories which had been shared in groups. This involvement by the participants in problem solving, leading discussions and activities develops feelings of self reliance, control and competence (Dalrymple and Preston-Whyte, 1994: 116).

Story telling was an important component of the workshop. In telling each other our stories it develops a process whereby we can receive feedback about what has happened to us. This 'witnessing' encourages people to develop a cognitive awareness of emotions experienced in the past, present and the possibly the future. It was used as a way to map changes in the participant's lives and triggered a reflective process in which the meaning of experiences was negotiated (Freedman and Combs, 1996). For example, the first narrative expressed in the frozen picture was interpreted by some members of the group as depicting a drunken male who had made three girls pregnant. This meaning was then negotiated with the frozen group who pointed to their own experiences. The actual meaning of the frozen picture or code described how a young woman started drinking after

becoming HIV positive, and became pregnant. The other part of the picture showed how she overcame her drinking problem, sought treatment and graduated with a healthy baby. This code was a useful way to encourage reflection on gender and HIV stigma within a prevention context.

Participants and recruitment

A preparatory meeting at which the core methodological principles were outlined was held with the Health promoters and peer educators. The same peer educators that had participated in the focus group discussion attended the meeting. They were hopeful that some of the issues that they had discussed could be further developed. A group spokesperson revealed on behalf of the group that although they were peer educators they would like to ensure that the researcher was aware that they were also members of the support group. This was a remarkable shift in that prior research on the HP project had not been able to work with the support group due to high stigma levels. In prior evaluations peer educators had never before expressed a desire to either disclose their status or highlight that they primarily saw themselves as support group members and secondly as peer educators. This may have been as a result of the relationship developed between myself and the research subjects. The participants had met with me several times in earlier years and I had facilitated a workshop with them. They were familiar with me and many of them had approached me in the past to address personal problems. This history may have facilitated the group feeling in which they were comfortable to share that they were living with HIV.

Procedure

The workshop began with a short introduction and negotiated discussion of the process of how the twelve participants would work together. The four men and eight women agreed to certain values that would underpin the group process. These included demonstrating that we trusted each other, that if we spoke about confidential issues the group would maintain the trust of confidentiality. It was also important to demonstrate consideration and care for each other and this was to be expressed by listening to each other and ensuring that all statements were received with acceptance and love. The HP had developed a similar way of working together in the support group prior to the workshop. This served to allay feelings of vulnerabilities that might otherwise have emerged. Expressive techniques or tools were developed to indicate when any of us were feeling emotional or physical

discomfort. Participants were free to use the 'law of two feet' and leave the group for a while. 'Laughter time' was introduced as a theatrical convention. At any given signal by the participants the group was encouraged to laugh as loudly as possible and to do as many silly actions as possible for a two minute period. This allowed people to escape from situations that they were uncomfortable with. It also allowed us to start analysing what laughter means to us in different situations.

Following this three facilitative processes were used drawn from Boal's TO (1979). These are standard elements of the DramAidE methodology. The first stage of this process "Knowing the Body," involves exercises designed to acquaint the *spect-actor* with their own body and create recognition of how the body can adapt and adopt repertoires of movement. The second stage, "Making the Body Expressive," involves games designed to get the *spect-actor* to use their body to develop new ways of expressing themselves that is more authentic to who they are. The purpose of this, Freire argues (1972a), is that people should be the subject of their own learning and so that they can be the authors of their own liberation. The third stage, "The Theatre as Language," gets the *spect-actor* involved in performance. Boal (1979) divides this stage into three sub - stages of which the second "Image Theatre" was adapted for the purposes of exploring codes (or Tableaux) drawn from the participant's lives.

For the purposes of the workshop these elements were used as research tools. The three elements were: 1) songs used to interpret personal meanings throughout the workshop; 2) games used to explore particular social and psychological realities; and 3) the creation and enactment of dramatic 'codes' and the use of these in the workshop to understand the HIV/AIDS context and challenges. The three procedural elements are described below.

1) Songs

A song that incorporated action was suggested as a way of warming up the group. Song functions as an important component in establishing both ceremonial and social gatherings (Durden, 2003). The use of these familiar songs and dances is common in community theatre and theatre for development practices and in DramAidE methodology (Dalrymple, 1995). It is 'ritual' activity used to initiate transforming passive spectators into active spectators (Buthelezi and Hurst, 2003). Each had a turn to lead to facilitate an improvised song and dance. The same melody was used and different words and physical expressions were incorporated into the song. Using movements and a familiar song had

the purpose of developing the involvement and confidence of each of the participants. This began the process of introducing the method of working together during the workshop. This method encouraged the creative expression of all of the participants within an environment that was non-judgemental. The participants' experience of the song and the key themes that emerged from this process were reflected on. This reflection introduced the seminal themes that would be investigated in greater depth during the games and frozen pictures. Central to this process was the understanding that people are the subjects of their own learning and not empty vessels to be filled by the knowledge of experts (Freire, 1972a).

2) Use of games to explore and interpret social and psychological realities

The purpose of playing games was twofold. Firstly the games encouraged an expressiveness of movement that is not usually encountered in everyday life. Secondly the games started a process of analysis and of questioning conventions that we take for granted. For example, a different way of counting was explored using a Boalian game. In this game body movements and sounds are used as a substitute for numbers. This drew the group's attention to the understanding that epistemological conventions can be changed. This game was used as a springboard to outline the broad parameters of the workshop and how all activities would be used as a way to reflect on and interpret daily life. The game also established that all activities examined how we relate to each other and the meanings that we derive from this.

The nature of the games was such that they were easily understood and adaptable to the needs of the group. The games were facilitated in such a way so as to ensure that the meaning of the game was constructed by the group. In this way the participants were able to construct a shared reality of themselves in their social context. This incorporates the process of challenging the idea that knowledge is something that people have in their 'heads'. It also provides an opportunity to reflect on and generate understanding of what they jointly know by virtue of shared types of experience.

The listening-dialogue-action framework was developed further. This was initiated by each person choosing an important story from their lives and creating a body sculpture (or tableaux) of a key moment of that story. This was used as a trigger to start discussion within the group. It also functioned to introduce group members to the coding and decoding process.

The group listened to each other's stories and discussed them together. The purpose of this was to identify common themes that linked the stories so that they could co-construct their stories into a group narrative which they shared. This draws on Freire's notion of drawing together generative themes into a physical form or code. This is often called a discussion catalyst or trigger. The purpose is so that participants can 'see' their reality with new eyes and consequently develop alternative ways of thinking and acting (Wallerstein and Duran, 2003: 42). This loose interpretation of Freireian method aimed to actualise their stories into a photograph of pivotal moments of themselves as subjects in their own recognised social context. This initiated a process of dialogue and the formulation of the ongoing interaction between reflection and action.

3) Working with enacted 'codes' to interpret HIV/AIDS change processes

In the workshop two codes were developed, each of which were recognised by the participants as being important themes drawn from their own lives. The process of developing the codes was prompted when participants were asked to have a conversation with one other person in the group and discuss a significant moment in their lives. It was explained though that this moment should be a pivotal moment in their lives. Boal (1979) refers to such a moment as a 'Chinese crisis'. A crisis is a moment of choice in which there is the potential for profound tragedy or an opportunity for change. Once the participants managed to find similar such moments in their stories they were requested to make a composite photograph of the pivotal moment of their story.

The process of analysis by those that were not in the 'photograph' was an exercise that enabled realisation of the complex way in which themes from our lives inter-relate and how our perceptions of 'moments' that are subject to interpretation, can have different meanings and has the potential to change. It is also descriptive of how we are in a process of "becoming" in relation to others and how slight shifts in the way we relate can create change (Freire, 1972a). The value of this exercise in the research process was that the participants investigate their own reality resulting in the production of a reflective process which empowers them to act on their own ideas. This is markedly different from a research process in which the researcher identifies themes based on his/her assumptions about the subject's reality.

The participants were asked to describe what was happening in the code and to discuss and interpret it. They did this by breaking into two groups to develop their own codes. They

then presented the codes to each other. This process first involved the presentation of one code which allowed for the participants not in that code to reflect on what they saw. The group presenting the code then revealed what their code was about and affirmed or refuted the other group's interpretation. The aim of this exercise was for the participants to locate "decisions within themselves" so that they can respond to situations posed with actions that are aimed at 'overcoming' rather than 'passively accepting the given' (Freire, 1972a).

Data capture

The participants were actively involved in generating the data and in capturing it. This involved taking photographs of frozen pictures or codes. Video filming activities focused attention on key aspects of the code that would be used in collecting the data. Some participants told their stories on camera. Some stories were written while other participants preferred to draw key lessons that they had gained from the workshop.

Data collection

The workshop was tape recorded and selections made with the assistance of the students and a Health promoter. Translations from Zulu were made verbatim by a non-academic Zulu speaking community member who was not a member of the HP project. The person who was to do the transcription was introduced at an earlier meeting and the group felt confident that they would transcribe the sessions adequately. A benefit of using a member of the local community who was not associated with the university (or the respondents) meant that with little vested interest in the subject matter events were interpreted on a phenomenological basis.

3. Post workshop focus group discussion

Rationale

The purpose of the discussion was to address issues that had not been raised in the workshop. The focus group discussion continued facilitating discussion "in which diverse perceptions, judgements, and experiences concerning particular topics can surface" (Lindlof 1994: 174). The first part of the discussion encouraged reflection on the methods used in the workshop leading to inquiry about the HP project and its role in revising stigma and gender norms.

The second part of the discussion encouraged participants to share their experiences of the HP project and reflect on how this has impacted on increasing access to treatment. This discussion focused on the impacts of the project in the lives of the support group members. Participants were then encouraged to discuss their understandings of concepts relating to HIV stigma and gender and reflect on positive and/or negative revisions of masculinity that can be attributed to the project.

The participants attending the focus group discussion had all attended the workshop with the exception of a one female student. Four males and eleven females were present. A senior HP was excused from the discussion to encourage free and open discussion.

Data capture

All the discussions were digitally recorded. This allowed for both visual and audio recordings. These were of interpretative value in the transcription of both ninety minute focus group discussions.

Data collection

The focus group discussion was used to elicit data that was added to the descriptive and exploratory nature of the workshop. The Freireian nature of the interaction established within the workshop was continued so that established group dynamics were able to further stimulate discussion, gain insights and generate ideas in order to pursue a topic in greater depth (Bowling, 1997 cited in Moodley, 2007). This differs from conventional focus group discussions in which the facilitator has a very brief space of time in which to establish a rapport with the participants.

ANALYSIS

Focus groups

Thematic analysis was used as the main process of identifying, analyzing and reporting patterns (themes) within the data. This process involves a familiarisation and immersion process in the recordings, transcripts and written materials, researcher's notes and pervasive ideas generated in the data collection process (Frizelle, 2004). Several close readings of the transcripts were conducted and this gave rise to thematic categories building on themes that had come up in focus group discussions and in the workshop. The most significant and central categories that came up in relation to the research question defined the themes.

Emerging themes and codes were identified and analysis made using a bottom up approach as themes evolved and then developed into main themes and sub themes. This process enables a conceptualizing of research data and classification of them into meaningful and relevant categories for the researcher to study unit(s) of analysis (Bowling, 1997). At the same time, as the study progressed it was informed by theoretical models of understanding. This impacted on the deductive component of analysis so that the final product is an inter marriage of inductive and deductive processes.

CHAPTER SUMMARY

This chapter has outlined in some detail the research methodology and the tools used in this exploratory case study. The workshop process was an integral part of the research exploration. The focus group discussions highlighted themes from the workshops and suggested that the key focus of the research should be an analysis of how young people are addressing stigma in their everyday lives by managing representations of their identities. This is discussed in the following chapter.

CHAPTER 4 - RESEARCH FINDINGS AND DISCUSSION

OVERVIEW

It is often said that all the members within any given community are to a greater or lesser degree living with HIV (Epstein, 2007). This statement is made in recognition that whether people are HIV negative or HIV positive the health of a community is dependent on its ability to ensure that all people are empowered to optimise their right to sexual health. The measure of the success of an HIV/AIDS intervention is therefore reliant on how empowered a community is to collectively work together to overcome the obstacles that prevent the practice of sexual health and accessing of the health services that support it (Cambell, 2002). Key to creating a health enabling context is to address the obstacles that marginalise people who are most at risk from HIV or are living with HIV from successfully participating in managing their health.

It was with this in mind that this study engages with students who are living with HIV and who by virtue of their own experience are able to shed light on how different manifestations of stigma create obstacles that make it difficult for mainstream HIV/AIDS intervention to be successful. The discussion of the findings is used to explicate a deeper understanding of the world in which young people negotiate living with HIV and highlights some of the key dynamics which shape their sexual practice.

The second section of the findings directs attention to what the HP project means to HIV positive students and highlights some of the unique features of the programme. Discussion of the research findings explores the 'subversive' role the HP project plays in mediating the way in which a generalised HIV mitigating intervention is experienced by those most affected by HIV. In the final section it is argued that the HP project poses an alternative approach to prevention which nurture a community based HIV/AIDS response that which is resistant to gender prejudice and HIV stigma. A summary of the themes explored in this chapter is:

- 1) Obstacles impacting on the effectiveness of HIV/AIDS interventions
- 2) The meaning of the HP project for the DUT HIV/AIDS programme
- 3) Reflections on the key findings of the study
- 4) An alternative approach to mitigating HIV/AIDS

1. OBSTACLES IMPACTING ON THE EFFECTIVENESS OF HIV/AIDS INTERVENTIONS

Interventions that continue only to impart information and not skills are doomed to failure in the opinion of the HPs and the students interviewed. Interventions need to seek to understand and address the complexities of people's lived experience (Harrison et al., 2000:286). As Campbell suggests "The forces shaping sexual behaviour and sexual health are far more complex than individual rational decisions based on simple factual knowledge about health risks" (2002:7).

The findings so far emphasise that gendered narratives in which desire, acceptance and fears of not conforming to hetero-normative scripts make it difficult for young people to rationally mediate sexual practice.¹⁰ Moreover experiences of 'failure to enact' the prescriptions of the populist slogan "It's as easy as A,B,C (Abstain, Be faithful or condomize)" reinforce feelings of low self worth and further stigmatise their sexual behaviour and identity. This plays out in the avoidance of situations in which young people are forced to acknowledge their personal vulnerability and take responsibility for their sexual practices.

Experiences of HIV stigma

The subjects of this study are all HIV positive. Many of them have been living with HIV for some time whilst others have only recently been diagnosed. Respondents indicate that they believe that HIV stigma is still prevalent at DUT, however, it is believed that enacted stigma (in which active discrimination takes place) is uncommon.

In the post workshop discussion, students living with HIV indicated that they would feel safe disclosing their status at the institution. They indicated that staff and student peers are supportive of those who have disclosed, however, they did point out that they still experience HIV related stigma. The HP explained that this experience is mediated by how well one adjusts to living with HIV, by perception and emotional wellness. He highlights that the personal and social experience of HIV stigma is reciprocal and that attitude plays an important role in shaping experiences of stigma and how people respond to you.

¹⁰ Chapter 1 (p.9) highlights why the mutability of language is significant in making communicative contexts ideal opportunities for creating new language, thereby negotiating new meanings for problematic beliefs, feelings, and behaviours. This has been found to be valuable in legitimating alternative hetero-normative narratives (Freedman and Coombs, 1996:29)

So if you are positive, as you are, you might take seriously what assumptions people make. There are always people who will say those things but you quickly learn it has more to do with you as an individual and how you think [that creates HIV stigma].

The findings suggest that recent diagnosis, less exposure to positive HIV identities and diminished social support led to increased experiences of internalised HIV stigma. Internalised AIDS stigma plays a crucial role in the emotional distress experienced post diagnosis with HIV. Common responses include guilt, feelings of anger and hopelessness motivated by the belief that they could no longer be able to consider themselves as 'normal'. This often led to depression and a desire for isolation. Without social interaction increased substance abuse was reported and obsessive thoughts about death and dying. Students said that they found themselves unable to counter this destructive spiral and this often led to them attempting suicide.

I used to be a drunkard because of my status. Because whenever I used to think about it [HIV] I used to hit the bottle. I used to hit it hard. It was my best friend. I was addicted to it... I seriously wanted to commit suicide. I tried a couple of times...

Negotiating a more affirming positive self identity is counteracted by the beliefs that the trajectory of the disease is a quick progression from diagnosis, to sickness and sudden death. This belief prevails despite peer educators and residence student indicating sophisticated knowledge about ART (Antiretroviral therapy) efficacy and disease management. Posel, Kahn and Walker (2007: 141) argue that even high levels of knowledge cannot counter social understandings of the disease in which HIV/AIDS associated death is seen through a lens that comments on the social and moral quality of life of a community.

HIV/AIDS stigma and gender norms

In the post workshop discussion HPs indicated that communities often have sets of competing beliefs about HIV/AIDS. Rational distinction is made that one cannot generalise about the kind of person that contracts HIV, however, people still subscribe to deeply entrenched beliefs about the 'type' of people who become infected. An HIV positive student described how she was labelled as "disgusting" because she was assumed to have contracted the virus because her sexual practice was excessive, immoral and possibly deviant. Posel et al. finds that many young people consider that death is the necessary price to be paid for the joys of freedom and this belief perpetuates attitudes that consider people living with HIV as deserving of their condition (2007:141). Most students acknowledge that increased social interaction with older peers, the availability of alcohol and drugs and a desire to explore their sexual identity often led to situations in which the desire to "want to do it" led to risky sexual experiences.

A high level of denial about their own risk is prevalent amongst students. Students in the post workshop discussion agreed that most people prefer not to talk about HIV or stigmas associated with the disease because they fear that it affects them personally. As the HP points out:

I think that one other thing that causes stigma is "no stigma" as such. [HIV/AIDS] affects them [students] so much that they choose not to react to it. They just feel that if they don't talk about it, it is going to be better than talking about it.

The participatory workshop found that students represented stereotyped stock characters like the "lover boy" and the "girl who has everything". The female character was depicted queuing at the clinic for the morning after pill while the "lover boy" was shown to be already involved in soliciting his next sexual encounter. The students pointed out that these are the 'types' that contract HIV because they participate in what is called the "dating race". This 'race' is associated with a lifestyle in which a student may have several sexual relationships to fulfil different emotional, physical or economic needs. Sex is often bartered for designer labels, cell phones, access to smart cars etc. It is also often used for more regular financial support (Posel n.d.:22). These students often have concurrent relationships with older men and women as well as people their own age.

It is this 'type' of student that often graduates with what is called a 'Double Diploma'. This refers to the certificate they receive for passing their studies as well as to the birth certificate of the child they have while completing their studies. A more sinister interpretation refers to the paper verifying their HIV status.

Students who are living with HIV anticipate that if people knew their status they would most likely be considered to be responsible for contracting HIV by having lived 'the life' outlined above. As previously indicated most students are well informed about HIV, however, people with HIV are assumed to be morally deviant.

...before it was out of fear that people reacted. Now it's out of disgust. They find it very disgusting. Other's they just don't want to know... They don't fear that you are HIV positive - it's not that. They just conclude that you're positive because of 'this'.

"This" refers to an association with a predatory male sexuality which is perceived to be "corrupting". Male sexual behaviour is attributed to be the cause for the high pregnancy rates as is suggested by this statement:

Everything is happening on campus. Men are corrupting everyone. They are all drinking [having sex?] and getting [women] pregnant.

Ratele and Shefer (2002) point to how gender differences and double standards play a role in the construction of promiscuity and deviance. Women with many sexual partners are regarded negatively as 'sluts' whilst men who have many sexual partners are regarded as exemplifying successful hetero-normative behaviour. The respondents pointed out that a man's 'success' is largely defined by his ability to find a partner or have several partners. This understanding is supported by Morrell (2000) who suggests young men often perform hetero normative narratives to affirm their masculine identity and to avoid social ridicule.

The corollary of this is that men are more likely than women to resist disclosure and often avoid using condoms fearing what inference their partner may make about the 'normalness' of their identity. Female respondents highlighted that this is symptomatic of the effects of gendered HIV stigma and how it leads to propagating unsafe sex practises.

It ...is this ego thing and they won't be able to propose. Sometimes it affects them...They are frightened they won't be able to 'do it'...People will say this one is HIV and they will run away.

A desire for acceptance and to be considered attractive was considered to exacerbate fears of exclusion from 'normal' hetero-normative practices.¹¹ Entrenched beliefs that we are biologically motivated to have penetrative sex means that men and women enact learnt gendered scripts which makes them vulnerable to risky sexual practices.¹² These scripts contribute to a lack of communication in relationships and this often means that men and women are not able to negotiate safer sexual practices. Campbell suggests that without family support affirming intimate social relationships amongst the young are often lacking. She postulates that unprotected sex may act as a surrogate for "emotional intimacy which is lacking in other areas of their lives" (2003:33).

Trust and intimacy were indicated to play an important role in defining the nature of sexual practice in the context of relationships. Men in concurrent relationships agreed that that

¹¹ Hetero-normativity (as discussed in Chapter 1, p.7) is rooted in socially derived expectations of how men and women should inter-act and is defined by beliefs that these norms are biologically driven and cannot be changed. For example, a dominant hetero-normative narrative which perpetuates unprotected penetrative sex as the norm is underpinned by gendered narratives which represent men as highly sexual and emotionally inexpressive and women as vulnerable and desiring intimacy.

¹² People enact social scripts in order to comply with dominant gendered narratives. The gendered narratives above are used to illustrate how they define male and female scripts. In the first narrative men feel that they need to conform to representations of male identity that is devoid of vulnerability and which is characterised by risk. There is a different (but related) script for young women. They use their understanding of the male narrative to distinguish between "bad" males (those who are emotionally inexpressive) and 'good' males (who set you apart from other girls). This perpetuates a cycle in which men in order to 'prove' their invulnerability practice risky unprotected sex. Women use their own 'script' to interpret this behaviour as increased intimacy and as an expression of emotional vulnerability. Thus both scripts converge to perpetuate normative narratives which play out in unprotected sex (see Firminger, 2006:298)

while it would be ideal to practice safe sex with both partners this was difficult due to social expectations. A peer educator explains:

I have two girlfriends [how] can I then tell you [my partner] that I am sleeping with that one. No, I respect you [both] so what can I do?

As the comment by a peer educator indicates in a context where there is mutual intimacy and trust condom use seem inappropriate. Unprotected sex in a concurrent sexual network increases the likelihood of HIV infection as it is shared amongst a small sexual network. This increases opportunities for contracting HIV as those who are newly infected have a higher viral load and are likely to have sex more often with the same infected partners than someone who is not in a concurrent relationship (Human Sciences Research Council, 2008).

In the exploratory peer educator discussion it was suggested that young women were found to consider themselves as defenceless against the sexual predation of men who are considered to be responsible for “corrupting them”.

....there is the power of who carries the condom... if a woman carries a condom she is called a bitch... if she carries a condom they say she likes sex – she is promiscuous.

Campbell (2003:127) suggests that in response to the stigma associated with carrying condoms and in order to avoid male aggression women often play into preferred narratives in which they enact scripts in which they play a passive role. This may result in men ‘acting out’ the expected more sexually aggressive role and young women become complicit in assuming the ‘victim’ role. This leads to both parties exempting themselves from taking responsibility for protection.

Gendered HIV stigma

Walker, Reid and Cornell (2004) argue that in order to understand South Africa’s spiralling HIV/AIDS epidemic, the role of gender, sex and power must be examined. Women’s experiences of living with HIV/AIDS and the stigma of HIV/AIDS are intensified because of their subordinate role in society (Soskolne, 2003:1).

Most experiences of enacted stigma are experienced by young women who by virtue of gender are often regarded as ‘soft’ targets for this type of bullying. Enacted stigma such as

“malicious gossip” and “labelling” often results in those suspected of being HIV positive being avoided for fear of being associated with the disease or even worse being considered HIV positive themselves.

A student describes how she was referred to as “that’s a Bad day”. The subtle use of euphemism was reported to often lead to the internalisation of discriminatory narratives and result in ‘self limiting’ behaviour. It was agreed that discrimination against people who live with a sexually transmissible disease is deeply entrenched. They are often regarded as ‘damaged’ and therefore social norms dictate that they should not associate with those whose who are considered as ‘healthy’ (Crawford, Lawless, and Kippax, 1997). HIV positive students observe this in interactions with their peers who express discomfort when HIV, relationships and issues such as dating are discussed. Positive students have internalised this belief as is suggested by the following statement.

You know [when] you are HIV positive, you can’t date because [that person] is negative. You must go for [someone] because you both are positive.

These beliefs are symptomatic of a wider discriminatory system that perpetuates ideas that HIV defines a person’s sexual being and precludes ‘HIV positives’ from a relationship with ‘negative normals’. Young people who suspect they are positive often delay testing for fear of a positive result and the shift that this causes in their self identity. A student who is a member of the support group described the behaviour of a young man who decided to test so that he could “propose love” to her. The understanding was that if he tested positive, then there would be nothing that would prevent them from having a relationship. She paraphrases how her current partner proposed to her after his test:

He said, “You see now we can date here’s no need for me to hide. I want you to be my partner because it won’t be a problem...I just wanted to propose to you but I didn’t know how to?”

It is interesting to contemplate the way in which fear, denial and desire play into this romanticised narrative. The statement above seems to suggest that ‘love’ motivates this young man’s preparedness to negotiate the complexities of an identity living with HIV. More importantly it points to a kind of fatalism in which a desire to be loved for ‘who you are’ is mediated through the stigma of one’s seropositivity.

Health services

Going for counselling and testing at the campus clinic was considered by most students to be a negative experience. Several students pointed that out that they experienced inconsistencies in the length and quality of the counselling and testing experience. Many felt that the counselling process in which risk is assessed made them feel stigmatised.

Questions such as: “What type of life are you living? What kind of a person are you?” – made me feel bad about myself.

An assessment of the counselling styles of nurses by the HPs suggests that given the pressures to keep the entire testing process under an hour leads to counselling and testing sessions being no more than education sessions. Nulty’s study on counsellor’s experiences of post test counselling finds that they often feel more in control when dealing with factual information (2005:3). This often translates into an educational question and answer session in which information is transmitted to the recently diagnosed.

Most students find that the clinics emphasise pre-test counselling and that in their experience the post test counselling process is not sufficient to contain the shock of a positive diagnosis. Students are counselled and then expected to leave the office without any further support. One student described the experience as “the loneliest moment of my life”.

....everyone will come and then they see you go into that room. Then when you come out [side] everyone can see if something is wrong...It was a room on the side...

The findings highlight an experience of counselling which Kippax (2006) suggests is as alienating as the sterility of the testing process. She notes that individuals are often relegated to the position of the 'uneducated' and the counsellor to 'the all knowing expert'.

Prevention for 'normals'

Rotheram-Borus et al. (2006:275) point out that testing for most life threatening diseases does not require pre-test counselling. They support other activists that suggest that insistence on pre- and post test counselling exacerbates perceptions that HIV is a dangerous and stigmatising process. The exceptionalisation of the disease is also considered to be a barrier to increasing the number of people who know their status. It is also considered to be a source of risk and harm to people with HIV (Judge Cameron cited in Gerntholtz, 2006:34).

The separation of systems of care for those who are 'negative' and those who are 'positive' initiates an experience that is felt to be discriminatory. Those affected by HIV are channelled into separate processes from those who have a negative status, Participant's highlighted how HIV is exceptionalised and how this impacts on interpersonal, contextual and organisational elements at the clinic. Positive students point out that this is experienced from the moment that they are received at the clinic reception, how the nurses facilitate the administrative system and by how health professionals treat them. An HIV positive student describes her experience:

You get this special treatment. Even the receptionist knows because 'we' are the ones that go straight through to the doctors - and they know what kind of people go straight to the doctor! The nurses also make a fuss and they'll even shout "it was just last week [you were here]! [That's] from the top of the queue, "Bring the girls from that side through". I mean...

This quote demonstrates that there is an urgent need for staff at the clinic to be trained how to ensure that the rights of people living with HIV are respected.

Feelings of outrage at privacy and confidentiality being compromised were strongly expressed in several anecdotes.

Exactly! [Laughter] So for everyone else they have to see the nurse and they even pull you to one side and so everyone sees, "Oh, they know you." So you

go first in the queue and you just know 'they know' and that everyone else knows now.

Students do not feel that they can access counselling or treatment at the clinic in a way which makes them feel safe and respected.

...it's also like the nurses think that if you are positive it's your right to know who else is. So they make it known to you and even suggest that you chat to them. Like I was sitting with one of the health workers and the nurse came and she made an example like – "you know this girl [so and so] her CD4 count is so low it's like 'something something'. She should start ARV's." It makes you wonder why she should come and make an example to you!

This exemplifies how ethics are often breached by nurses who talk about patients, point out members of the support group and talk openly about those who are experiencing treatment problems or who have recently tested positive. Speculation on the intentions of nurses and care workers suggested the rationale underlying this behaviour was that HIV positive people "should help each other". This interpretation is symptomatic of deeply entrenched attitudes which are historically rooted in beliefs that those who are 'contagious' should be separated from 'normal' society (Marais, 2005). This separation also functions to validate the nurse's identity as a healthy 'normal' who by distinguishing herself as different from an 'infected' or at 'risk' group is able to affirm her moral superiority as a medical 'expert'.

As a result of the limitations of the service offered at the clinic students are forced to go to private doctors for treatment. HIV students explained that because of internalised stigma they do not take advantage of economic opportunities to supplement their income. As a result they find it difficult to afford private doctors. Negative experiences with doctors also prejudiced them against seeking professional help. The HP explained that doctors have difficulty in communicating specialist medical information in a way that the patient could understand. This was often because of cultural and language differences. The consequences of this resulted in some serious communication misunderstandings, especially with regard to ARVs. This was often because of cultural and language differences.

Most people they end up going to private doctors who don't understand how to explain ARVs and people need to know what these tablets do because if they don't the treatment won't help... everyone knows about the side effects of them... but who do they talk to about them because the doctors and nurses say "take them or die."

HIV is a serious health condition and doctors are expected by virtue of their training to treat a disease informed by their bio-medical expertise. As is the case with counsellors (discussed earlier in this section) and some doctors this can lead to the objectification of the person with HIV whose disease is treated while their psycho-social needs are often not engaged with. This pathologises both disease and the person which reinforces feelings of difference, shame and stigma (see Kippax, 2006).

2. THE MEANING OF THE HP PROJECT FOR THE DUT HIV/AIDS PROGRAMME

The meaning of the HP project is defined by the young people who have initiated what management terms, "a dynamic shift in the way that communication about HIV/AIDS is experienced". The HP highlighted that the project has marked a radical departure from the way in which HIV/AIDS interventions had been facilitated in the past. The project is developed according to how young people direct the programme which has meant that they "own" the project. This is largely because of the way in which the project engages with young people. This approach encourages them to engage with their own specific experiences of HIV/AIDS.

Creating a dialogue on gender and HIV stigma

The HP stresses that the project is not about communicating information and education about the disease like most HIV/AIDS interventions. He elaborates that this project is about creating "personalised opportunities" for young people to explore in an experiential way what HIV means to them and the DUT community.

This means creating a space for young people to tell their stories using a range of activities that use song, dance and drama to give expression to:

...the things that they fear to talk about and have never shared before. This helps us to talk about where we come from, how we live, our relationships and the secret things that we don't [normally] talk about...

A student points out that being a peer educator is an affirming experience in which they feel respected and listened to. The individuals in the group are encouraged to use their own expertise to cope with the issues HIV presents.

Yes, we learn from each other's lives and about helping each other to cope with HIV in our own way.

The experience of resolving problems in a group context counters feelings of isolation and hopelessness.

It [the project] gives us hope because we see that HIV/AIDS is not about being sad it's about being there for other people.

A positive approach to HIV/AIDS

Unlike most prevention approaches the emphasis of the project is on the positive way in which people are able to cope with living with HIV in their communities. The project therefore:

...engages with people in ways so that they learn to 'see themselves' in a different way...so our main duty as HPs is to create the space for them to see how good they are and that they are changing their lives...

The approach encourages people to recognise how well they manage their HIV risk rather than pointing out less successful behaviours which might build into feelings of failure, reduced self efficacy and fatalism. This approach is dynamic and flexible so that “we move with people in a way that they want to move with.” The HPs and peer educators try to ensure that activities and events are engaging and exciting to attend. A peer educator highlights that this means that when an activity is planned people are involved as much as possible. This is done with the recognition that:

These are people, human beings, people who talk, who think, [who are] involved in different activities, so we must be creative, and make sure that their best shines.

The project therefore acknowledges an intelligent public which is highly critical and which is unlikely to respond to didactic messaging and imperatives to ‘change behaviour’. The HP explains that “the reality of his own life” and the way that he lives with HIV in the “eyes

of the community” creates an opportunity “so they can examine and think about themselves and their role in the community.”

Developing a context of care

This understanding has prompted a responsive approach which is sensitive and acknowledges that the student population is deeply affected by HIV “emotionally, physically and even spiritually”. A peer educator explains her understanding of why the project is meaningful to young people:

...it's about the personal reality of being a human being and moving forward.

We help each other to find a space to cope with HIV in our own way.

Central to the HP's relationship with the students is respect for other people's knowledge and an understanding of the role of the facilitator. This understanding is underpinned by the recognition that they cannot think for the students or impose their own knowledge on others.

My role is to facilitate the knowledge that we have together to channel it in the right way. Sensitivity to group dynamics and how you handle them is important.

I help people to examine their role and when they think about this, they look at themselves and this helps to empower them.

The context in which communication takes place encourages opportunities for dialogue and the sharing of lessons drawn for the life of the HP.

...It is a comfortable space which is the right place to talk. I acknowledge them for who they are, their opinion is respected, and they are sharing challenges which they are also facing.

Students work from within the current preventions system and use their influence as peer educators to moderate the effects of systemised discrimination at the clinic. A young educator describes how she tries to ensure that young people do not experience the feelings of shame and abandonment which overwhelmed her when her hour for counselling was over.

They would come out and you would see their eyes are red. I would ...talk to them if they knew me or if they looked as though they needed someone. I

promise you it helps sometimes. Even if it's just to make them laugh or cry. Just so they don't leave holding all that emotion. It makes it normal.

Increasing access to counselling and testing

The HP persona plays an important role in the lives of both the peer educator and support group and is held in high regard. The HPs play a role in providing tangible embodiments of qualities which young people feel are more important than one's HIV status.

We forget his status; we admire him so much as a person. He does not preach but practices strength and positive living. He is a leader and I have taken this into my life.

As the statement above suggests young people are inspired to adopt these qualities and practice them in their own lives. Students find that this begins a process whereby they are able to develop new skills, which enables them to develop confidence. Emotional readiness is an important consideration when going for counselling and testing and is a strong predictor of the ability to cope with a HIV positive diagnosis.

Students report that pre- and post test counselling with the HP is a positive experience. They point out that contrary to their experiences with 'expert' counsellors they feel listened to.

...she gives us the space to tell our stories because people don't just go for an HIV test but they go to sort out their other issues...and you can easily talk to her...

Peer educators also point out that not only is the skill of a counsellor an important part of the testing but that an environment in which one feels respected builds confidence that confidentiality will be maintained. The HP project has relocated itself from the clinic and is now housed separately. This student friendly environment has led to an increase in the number of students testing. More significantly it has enabled more males to go for testing and to join the support group.

Disclosure and positive living

A shift away from encouraging disclosure while exposing people to engaging and inspirational personalities, is a mediating factor that revises stigmatised identities in a way

that does not encourage the adoption of particular behaviour or endorse people to act “positively”.

The programme is not just a social programme, it goes beyond that, it's about helping people to empower themselves to how to deal with circumstances around HIV/AIDS. It's about how to be strong, to move forward...

This is of some significance in that living with HIV is negotiated through group processes and reflection on what these mean for the self. There are few external demands made on the individual's responsibility to refashion themselves through an individualistic 'self-help' and 'caring for the self' approach (see Robins, 2007). The HP emphasises that disclosure is a matter of choice and not entered into without due consideration.

Being HIV positive doesn't mean you need a support group – that classifies people in a category. Disclosure does not motivate people, but considering it rather forces you to think about where you are [how comfortable you are with your status].

A social network of peer educators works towards creating a supportive environment that is lively and encourages people by creating experiences that reinforce self concept.

The support group provides a safe space which gives people permission to acknowledge the more painful aspects of living with HIV.

A lot has changed [since I joined the support group]...A lot of things just sort of opened up for me like you can't believe...I had a lot of anger within me ever since I found out about my status. This was two years back. I carried it. But when I went with the group on a weekend retreat something just burst. I was just walking with ...[the HP] then he confronts me [about my problem] and made me see my anger. He helped me learn to cry. That was when there was a turnaround in my life and I started to look at things in a different way...

This space allows for what Stein et al. (2003) refers to as a 'nuanced identity' in which realistic acknowledgment of 'negative' emotions does not compromise a positive and affirming sense of self. This nuanced identity, she hypothesises, helps people to counter the guilt of feeling 'negative' emotions and feelings of not being able to cope.

Ya. Now I accept my status. Before then, I feel embarrassed to say, I went to those lengths [drinking so much]. Such a lot has changed. It is like meeting here today - when I go home and I think about what we have shared and what is happening here. You get to see this has made an impact in your life especially with what comes out of here [the HP project].

Discussion on what had happened to make the situation 'different' suggests that the support group provides both a formal and informal network of relationships in which new members can help those newly diagnosed come to terms with their emotions of loss, anger and despair.

...But they [the support group] wouldn't let me. They would phone me all the time and visit all the time - without telling me they were coming. I didn't get a chance [group laughs].

The support group and witnessing community participation in HP project activities that demonstrate a supportive attitude towards people living with HIV, develop feelings of self worth and increase confidence in the ability to cope with living with HIV. This develops resilience and lays the groundwork for a more enduring and adaptable self concept (Stein et al., 2003).

Modes of engagement

The project has developed an eclectic range of communication modes which draw on traditional and popular art mediums in assisting campuses to construct health messages and popularise resources. Different formats appeal to people and make HIV/AIDS interesting. A range of media (or modes of communication) are experienced by participants and serve different purposes. For example, workshops have their own unique set of outcomes; performance orientated community open days are about reinforcing positive values and community solidarity; ritualised quilt ceremonies are used to symbolise those lost to AIDS and memorial services to remember the unique value that people have added to the community.

Core to the effectiveness of communicative contexts is the persona of the HP. Living openly with HIV in a public way opens dialogue on the representation of HIV positive people. The HP is critically aware that people are challenged by someone being open about their HIV status and that some people have strong feelings about those infected. The HP is sensitive to this and so tries to ensure that all interactions appeal to the people involved.

...It starts with how I project my personality, my appearance, how I handle attitudes. I make sure that I am always able to make time to attend to students. They also know that I am up to date with information as well as the fact that I respect their knowledge. My role is to facilitate the knowledge that we have together to channel it in the right way. Sensitivity to group dynamics and how you handle them is important. I help people to examine their role and when they think about this, they look at themselves and this helps to empower them.

In a period of history where the genres of reality television and the dramatisation of events happening to real people are recognised as entertainment in the media it is little wonder that the life of the health promoter is compelling (see Schechner, 2002) The HP can thus be interpreted as a dramatic medium who embodies media message and the modality-persona through which messages of “how best” to live with HIV is made possible. This provides an alternative to media stereotype representations of people ‘infected with HIV’. This mitigates against the idea that people living with HIV are promiscuous, irresponsible and in some way deserving of the disease.

Creating a space for change – the DramAidE workshop

Transformation seems to happen in the spaces or opportunities that the HPs provide for people to make new meanings of their experiences of stigma, gender and HIV. It was found that this happened most often in the safe space of participatory workshops facilitated by DramAidE and the HPs. A respondent makes reference to the transformative impact of the workshop experience in his life:

...These workshops bring out the hero in you... I am not afraid anymore from these workshops...and we recognise we are leaders and are responsible.

The workshops seem to create opportunities to 'act-out' idealised notions of the self which are often difficult to play out in everyday situations. This quote suggests a degree of critical thinking which develops increases in self concept:

... we no longer do things without thinking - because of the HIV/AIDS unit here - our friends, families our fellow students have been helped...the way we talk now.... we involve people... We run workshops everyday of our lives...

The last part of the statement seems to suggest that the workshop culture has been incorporated into lived experience. It is important to note that the workshop experience provides an environment which is closer to that of a social club.

...Talking [together makes us] feel more comfortable as this is like a social club and encourage them to feel that they have a space to communicate and feel supported, share information together. It gives them the space to choose where they want to be [as there is no pressure to disclose].

A method for revising gendered narratives

Students identify workshops as one of the most effective communication modalities of the HP project. Students claim to have learnt to reflect more critically on their own behaviours in relation to HIV/AIDS and gender awareness. Workshops are also claimed to develop critical thinking and develop personal confidence.

The participatory workshop process was used in the context of this research project as a springboard to introduce a process of critical inquiry into how gender is coded into everyday activities. This was found to develop nuanced understanding of the risk context

which young people negotiate living with HIV. A workshop participant notes on his general experience of the project:

We play all sorts of games. Some games are for boys and some for girls. I can see that even the games that we played together[as children] are about 'choosing' or 'testing' them [a potential partner/friend].

In the participatory workshop process students found that games can be used in an innovative way to examine how learnt childhood gender narratives impact on adult narratives. For example, an inquiry into the nature and meaning of 'dating' in the context of student life was linked to developing an understanding of this behaviour as 'play'. Discussion explored how in order for 'a game' to be successful it has to follow certain social rules or scripts. Role playing then presented young people with the opportunity to enact various strategies so that they could change the 'most' conventional script considered to create the context of risk.

It was interesting to note that the emotional intensity of 'play' is underpinned by the conscious recognition that 'this is not play' and that there are formats to social conventions and that these can be changed (see Berne, 1986:25). Students find that once there is recognition of the format of a game it is considered to become more predictable, controllable and intelligible to the person. 'Acting out' games that are 'taken for granted' is found to facilitate critical appreciation that convention is open to change. Students elucidate on their experiences of the game during the participatory workshop:

It was confusing. You have to keep changing. You're used to a certain way and now [new] movement and funny sounds. So it's like totally different. Lots of changes!

You start off with something you're used to - then you start adding things and doing different things and it changes it completely... it makes it difficult because in the back of your mind you are thinking [this is not what I am used to]!

This interchange suggests an awareness of the difficulty of learning new scripts.¹³ The comments highlight recognition of how a new game with unfamiliar formats is difficult to play. It explicates how certain conventions of speech and movement are needed for

¹³ See Chapter 4 (p.62) for an explanation on how scripts inform sexual practice.

communicative exchanges to have a meaningful outcome. In other words, the cues have to be given correctly and be recognisable. The new cues become more intelligible with more experience of the formats.

The more you change it the more difficult it is to adjust. Eventually you get used to it - the more you do it the easier it gets.

Yes. It's like every day you have to learn to adjust to change...

These comments demonstrate that there is awareness that by changing a conventional 'script' the potential for new patterns or repertoires is created. It further suggests that by developing consciousness of the rules and consequences of a game one is enabled to have more control over the outcome.

Students found that a method called 'freeze frame' was a useful and exciting tool in creating an appreciation of how the body draws on memory and experience and replicates this in everyday life (Boal, 1979). Central to this process is isolating physical expressions which the students consider to be worthy of discussion. These expressions are explored in a sequence of 'frozen frames' so that they can be analysed to gain a deeper understanding of common narratives. Participants comment on the experience of this technique.

It's unusual. It's not something that you do every day. You don't take a part of your life or an important part of your life and portray it in a picture. It's different from drawing because you physically are there in the picture and it brings back those feelings

These 'frozen' moments are recognised as critical moments that have played a role in shaping the participants' lives in the present.

*...it's a different way of working. It's practical. It's hands on. It's not like a conversation where you are learning, **this is real** its hands on.*

Students when they 'work with the body' find that they are able to develop an appreciation of a more complex range of physical expression. This is because drama includes a form of cognition that is not strictly conceptual but rather sensual (involving the stance of the body as it is located in a specific situation) and imaginative (involving the creative moment) as

well as suggesting new experiences (Jameson, 2000). Increasing understanding of repertoires of emotion and how they are expressed physically is found to be useful in deepening an appreciation of personal experiences of 'pleasure' and 'desire'. This enables them to analyse culturally conventionalised notions in relation to their own experience.

Learning skills to address gender and HIV stigma

In the both the exploratory and post workshop discussions students indicated that the workshops were a valued space in which they learnt communication skills. Young women reported that these skills enabled them to cope with and counter stereotypical roles and situations where patriarchal power is taken for granted. Female peer educators noted during the exploratory focus group discussion that they had developed confidence in their capacity to communicate more effectively.

Wena...if a boy sat next to me...I could cry inside...I was so shy - if he would say something to me. Now I know that I can cope and communicate. Tell him off...[laughs].

Young men point out the dire need for more gender education particularly where abuse against young women is rife. Students commented on reformed perceptions of the opposite sex and the development of communication skills:

Gender workshops are important... I used to be 'the man', you know, how it is...[playing with his dread locks]... But now, I understand that females... [touching the leg of a young female sitting next to him]... are real human beings, have great minds and make a positive contribution to society – I also learnt that men are [sometimes] dogs...[laughs - tapping his chest]...

One of the respondents noted that as a result of the workshops he has developed a reformed understanding of his masculinity and the ability to express the qualities he considers to be necessary for successful fatherhood.

What if you have a situation in your family? When someone (like your son) comes to you, you listen and can understand - so if my son has a problem it helps me to be a better father...husband...

Young men are seen in these workshops to contest stereotypical images of masculinity, reconsider their roles as partners and fathers and reflect on notions of sexuality which are

harmful to both themselves and society. The project provides the opportunity to develop positive male self images and reinforce the value of successful fatherhood. Successful fatherhood is linked to improved emotional health and self confidence, the inability to sustain intimate and supportive relationships and decreases in gender abuse and violence (see Robins, 2007).

Revising HIV stigma

Discussions before and after the participatory workshop highlighted that peer educators find that workshops provide opportunities for an enjoyable learning experience. Workshop forums also develop skills and qualities which assist in developing resilience and optimism. The initial part of student training is to develop an understanding of how HIV affects people both individually and collectively. This involves the practice of developing listening skills and learning to demonstrate empathy and caring in listening to people's stories. Sharing stories and reflecting on possible alternative endings encourages recognition that with the appropriate skills an individual can counter HIV narratives which often seem helpless. An HP comments:

Stories are very important, everything we say or hear [listen to] has meaning. I can see that people respect me when they listen and then I respect them back. We look at the problems and it makes us think about what made things like that happen. I have learnt a lot from stories...sometimes we can help find out what good things come out of what happened.

Storytelling amongst students also develops an appreciation and respect for people who are different from themselves. This is a fundamental component of the project and leads to a nuanced understanding of injustice. A young woman describes how stories sensitise one to how other people experience life:

In the activity group there were many different people and when I heard their stories I felt bad. I want to make a change. I was quiet then but now I am open. I know that my peers have expectations about my behaviour and I want to be that person.

The HPs find that story telling encourages recognition of how stories all share similar experiences of life. This bonds the group, increases feelings of empathy and develops a sense of solidarity which strengthens respect for each other. The HPs noted that this is a

useful method for developing an appreciation of the need for students to respect each other and develop a culture in which human rights are valued. Students consider themselves as activists who address not only stigma but also other issues of justice. Students report that victimisation of marginalized learners such as unprepared students from rural areas, South African Developing Countries (SADC) students, gay and lesbian people, as well as street children who make their way on to the campus) are on the decrease as a result of the project. As the student below indicates the HP project has meant that young people at DUT recognise that there is a strong awareness of the need to address power inequalities and resulting oppression.

We are trying to fight stigma – I correct those that I walk with when they call each other names...we speak out...

3. REFLECTIONS ON KEY FINDINGS OF THE STUDY

Mainstream HIV/AIDS interventions which prescribe 'behaviour' change were found to exacerbate HIV stigma and do not adequately address the social norms that create contexts of risk. This raised questions as to the appropriateness of mainstream prevention messages like 'be faithful' or 'use a condom'. These value-driven imperatives do not seem to sufficiently take into account the complex sexual networks and the normative context which structure the 'realities' of people lives and the different types of sex and relationships they choose. As Shapiroa and Ray (2007:68) argue, programmes need to acknowledge a person's 'actual' sexual relationship(s) in the context of lived experience and socio-economic situation, and his/her specific needs for sexual information.

The research highlighted that gender identity plays a key role in high-risk sexual behaviour and that young people's sexual encounters are negotiated within a context where dominant gendered narratives make men and women prone to perpetuating stereotypical scripts. Entrenched gendered narratives were found to reinforce HIV stigma and perpetuate social constructions in which women are helpless victims of male sexuality. These findings were consistent with literature that suggests that a key obstacle to mitigating HIV is HIV stigma which prevents people from accessing counselling, testing and treatment services see (see Robins, 2007; MacPhail and Campbell, 2001; Berger, 2004).

The findings agreed with literature that indicated that men are less likely to go for testing, become involved in support groups or consider treatment because of the perception that clinics are not 'male-friendly' (see Peacock, 2005; Fuleihan, 2006 cited in Robins, 2007:9). These findings highlighted the need for HIV/AIDS interventions to recognise male vulnerability by avoiding 'blaming' attitudes towards men which often result in increased stigmatisation of HIV/AIDS services.

It was also found that HIV prevention needs to address the needs of young people who are most at risk for HIV/AIDS stigma and being marginalised. More specifically, findings indicated that that HIV/AIDS interventions need to reconsider the current prioritisation of HIV infection. As Shapiroa and Ray point out, almost twenty five percent of all new infections globally are in adolescents and young people (2007:69). As these young people mature they need age appropriate sexuality education, information and support.

In the post workshop discussion young 'HIV positives' stressed that current prevention interventions all assume that their target groups are HIV negative and are only concerned with preventing infection. The HPs pointed out in this discussion that in resource constrained settings like higher education where young people do not have access to treatment literacy programmes an important consideration in mitigating HIV/AIDS is to prevent re-infection. Re-infection with resistant HIV strains often means that ART combinations quickly become ineffective and lead to people who have higher viral loads. This means that they are more likely to pass on a higher concentration of the HI virus and are thus more infectious than those who have not been re-infected with the virus. The HPs felt that this is a matter that needs urgent attention because most prevention programmes are only concerned about the initial infection. Ray and Shapiroa conclude that prevention in consideration of this should be concerned with (re) infection (2007:71). The concept of (re) infection is relevant to both 'HIV positives' and 'normal negatives'. Nor does the concept reinforce the implication that prevention of infection is not a key concern for people living with HIV.

Research other than that of the current study also sustained that young people don't access counselling and testing services. Post workshop discussion with the HIV positive group of students found that they experienced a 'disconnect' between their needs and the way in which the counselling was conducted. HIV positive students highlighted that they often did not go back to the clinic as the only treatment provided is vitamins. This is of

significance given a growing body of literature concerned with the role of pre test counselling in attempts to encourage more people to find out their status in contexts in which treatment, care and support services have not been implemented as part of a more comprehensive response to health care with HIV (see Koo Bergier et al., 2006; Rotheram-Borus, Liebowirz, Etzel, 2006). The findings suggest consensus with literature which shows that young positives especially need appropriate sex-education, support for dealing with sexuality and self-identity with HIV (see Shapiroa and Ray 2007).

4. AN ALTERNATIVE APPROACH TO MITIGATING HIV/AIDS

The key conclusion of these findings suggested that there is a need to subvert current prevention interventions which provide didactic 'expert' solutions to HIV/AIDS which young people are expected to implement.¹⁴ These solutions do not consider the specific context and needs of young people. These interventions perpetuate communication strategies that emphasise that knowledge and rational informed choices information equals prevention.

The HP project was found to provide an alternative to mainstream prevention interventions. Discussions with management from the HIV/AIDS programme and students affected and living with HIV indicated that the project's strength lies in its unique approach in engaging different sectors of the DUT community to participate in a dialogue on HIV/AIDS. The effectiveness of this dialogue based approach was found to lie in the experiential nature of activities and events which were used to generate discussion. Student discussions suggested that student willingness to participate in HIV/AIDS related campus structures and organisations increased significantly as a result of the HPs leadership approach. This approach demonstrated confidence in the ability of young people to find their own solutions to address HIV/AIDS. Students highlighted that the HP project has played an instrumental role in revising communication about HIV/AIDS within the institution, which prior to the HP project was experienced by students as 'authoritarian' and in which they had little input. These findings are congruent with literature that suggests that institutionally based approaches to HIV/AIDS interventions often undermine the social capital of young people.¹⁵ Formalised structures within institutional systems are implicated in reproducing top down approaches which curtail opportunities for young

¹⁴ Subversion is a post-structuralist concept which is concerned with the mechanisms whereby social structures and cultural formations connected with power structures producing hegemony can be altered by subversive (undermining) practices (see http://subversivmesse.net/about-en/issues-themes/articles_2009). For example, this study draws attention to the role of the HP project in subverting HIV/AIDS interventions characterised by a 'top down' approach to health promotion. This approach situates people living diagnosed with HIV in the disempowering, homogenising position of 'patient', 'victim' or 'Other'. In effect, the HP project is found to diminish this system of control by subverting and interrupting the social milieu which sustain it (see McLoughlin, 2006:7).

¹⁵ Chapter 2 (p.27) highlights social capital as an important approach in the development of a health - enhancing community. Of significance to this study is how improved social capital enables the development of a supportive social and community context that supports the renegotiation of HIV stigmatised identities.

people “to develop a sense of critical confidence in their ability to shape their lives, or by implication, to take control of their sexual health” (Campbell and MacPhail, 2002:8).

A significant finding has been the recognition by students that the HP project has played an influential role in enabling them to revise the stigma associated with an HIV identity. Discussions held with students living with HIV during the workshop component of the research showed that peer education activities enabled students who were affected by HIV/AIDS to collaborate with students negotiating an HIV positive identity in organising activities and events. This experience was found to increase perceptions of the institution as a caring and supportive environment and had the effect of reducing HIV stigma levels. This was found to increase the confidence of people most affected by HIV/AIDS in that their needs are being addressed and led to increases in the uptake of counselling, testing and treatment services.

The project’s approach was found to empower young people who are living with HIV to lead a prevention approach to mitigating HIV that affirms recognition of the risk management practices that they are able to perform. This is in contrast to prevention interventions in which an emphasis on disease and disease prevention, sexual violence, infidelity and difficulties in negotiating condom use is found to be overwhelming. The HP project was found in turn to recognise that there is a need to understand the important role desire and pleasure play in mediating sexual practice. This finding was encouraging considering the growing evidence of local and international research which shows that linking messaging about the practice of safer sex with ‘pleasure’ leads to increased and consistent use of condoms and the practise of safer sex (see The Pleasure Project cited in Shapiroa and Ray, 2007:76).

Current trends to desexualise the epidemic (dissociate pleasure from sex and HIV) and promote concepts of abstinence and faithfulness as key components of higher education interventions were challenged by the drama methodology employed by the HP project (see Berger, 2004). This enabled young people to explore via a participatory workshop model a method to interrogate gender and HIV stigma (see Kelly, Erdman and Cook, 2007; Berger, 2004). The value of the participatory workshop mode seems to lie in its ability to act as an impetus to create an empowering context for male hetero-sexuality to be witnessed as socially accountable and refashion itself within modes of sexual responsibility and empowerment. The testimonies suggest that improved communication

between men and women creates opportunities to explore new modes of sexual responsibility and an environment in which new norms can be considered and practiced.

The project was found to have developed a context in which young men and women feel safe to problematise masculinity. Importantly, the HP was found to embody positive qualities which increase self efficacy and the uptake of counselling and testing services by young men. The health promoter's HIV status and the challenges it presents are recognised by students, empathised with, and is a stimulus encouraging increases in access to testing and treatment. The findings from the participatory workshop suggested that there is correlation between demands for medical services when more complex gendered narratives are prevalent. These finding were supported by recognition that young men and women demonstrated that they are able to work together to create a communicative context in which gendered narratives were recognised as changeable and controllable.

The Health Promotion project was found to provide a context for the development of young peoples' critical consciousness about their sexual health. Finally, the findings suggested that that the HP project promotes a context within which young people can collectively develop the belief and confidence in their power to resist dominant gender norms, in the interests of being able to assert their sexual health.

THEORETICAL REFLECTION

Central to Freire's methodology (1972a) is the understanding that education of any kind is implicit in the oppressive social reproduction of class, ethnicity, racial and gender structures. Critical consciousness and the ability to organise against repressive practices is a key component of Freire's liberating pedagogy. He cautions however, that life situations characterized by exploitation and oppression lead to the development of adapted consciousness rather than critical consciousness. Adapted consciousness refers to a state where "a person accommodates to conditions imposed on them" (Freire, 1972b).

Freire (1972a) highlights that the interests of those maintaining the status quo lies in changing the consciousness of those who are 'oppressed' so that they can adapt to the situation they find themselves in. This is exemplified and perpetuated in the idea that people living with HIV are individual cases who deviate from the general configurations of a "good, organised and just" society (Freire, 1972a). In the context of this study, the

expectation that people should 'adapt consciousness' is recognised in the oppressive way in which people who are living with HIV are pressured to reorient their identity to conform with societal norms in which people with HIV are stigmatised. An 'HIV stigmatised identity' construct hinges on the success of one group in discrediting another by virtue of the imposition of moral authority (see Parker, 2004). This power is asserted over the stigmatised group by exaggerating their difference from the main group. Freire (1972a) highlights this active struggle for dominance between the oppressors and the oppressed.

Paulo Freire (1976) in his book, *Education: The Practice of Freedom*, explicates the framework of his methodology and articulates key constructs that form part of Freirian method and which can be used programmatically for empowerment (cited in Sharma, 2002). Dialogue, conscientization and critical consciousness are core tenets that inform transformation and the renegotiation of identity within the HP project.

Dialogue between peers is an essential component of the HP project and provides opportunities for young people to assimilate and develop a language of alternative behavioural norms and options in their own terminology and in the light of their own priorities (Campbell, 2002). A central component of dialogue is learning to perceive social, political, and economic contradictions and to take action against the ways in which they perpetuate inequalities (Freire, 1972a).

The process of conscientization is readily apparent amongst the members of the project who are highly knowledgeable about their own realities as young people and the challenges of gender and HIV, and how this impacts on prevention. The extent to which the participants were able to identify the key issues that make prevention education exacerbate gender related anxiety and HIV stigma, demonstrates a deep understanding of underlying systemic forces of oppression. The discussants ability to think critically is characterized by the dynamic interaction between critical thought and critical action which was exemplified by their ability to think holistically and critically about living with HIV in a 'positive' way.

According to Freire, critical consciousness involves an "active, dialogical educational programme" (1972b), where learners are actively involved in formulating critical analyses, and generating scenarios of alternative ways of being. This process implicitly encourages

the 'adversely' affected group to bring about structural change within the social, political, economic and educational institutions of society in which oppression is complicit.¹⁶

It has been found to be useful to draw on Gramsci's notion of hegemony (1971) to highlight how the HP project uses a persuasive model of engagement to subvert HIV/AIDS interventions which are prescriptive and didactic. It should however, be noted that this concept is usually concerned with the dynamics of structural change involving the mobilization and demobilization of whole classes which is not addressed within the scope of the present study(see Connell and Messerschmidt, 2005:833).

It is suggested, however, that the HP project's capacity to mobilise leadership in society has resonance with Gramsci's (1971) concept of the organic intellectual. This concept recognises that ordinary people can be leaders of change and have the potential to interact with a community in a liberating way. The study therefore motivates that the HP project embodies a moral and ethical leadership which motivates a societal shift in which HIV status becomes normalised. This implies a conceptual framework of hegemony which is not only situated in regressive 'dominative' formulations of hegemony, but in progressive 'aspirational' hegemony engaged in movements towards future change (Howson, 2006).

RECOMMENDATIONS

Despite concepts of participation and partnerships and empowerment being considered crucial components of the higher education response, understanding of the processes whereby they might achieve proposed beneficial effects is still in its infancy (Communication for Development Roundtable Report, 2002; Campbell, 2003:1). This study suggests that higher education needs to consider the voices of those who are affected or living with HIV more seriously. They are able by virtue of their lived experience to inform prevention programmes and to address fundamental issues of concern. In health

¹⁶ The concept of hegemony considers men to participate in a complicit form of masculinity to receive the benefits of masculine dominance. Hegemonic masculinity is not achieved through violence. It is more often associated with an ascendancy achieved through culture, institutions, and persuasion. In Chapter1 (p.11) it is suggested that this provides the opportunity for a 'struggle' for hegemony, in which older forms of masculinity can be displaced by new ones. This highlights the potential for a more humane, less oppressive, masculinity to become the dominant hegemonic norm. This is part of a process leading toward an abolition of gender hierarchies (Connell and Messerschmidt, 2005:833).

contexts they are able to make recommendations and initiate change that facilitates the improvement of current systems.

CONCLUSIONS

Research on community based HIV/AIDS interventions that support action-orientated learning supports the findings of this study which highlights that in the process of mobilising others peers transform themselves (Freire, 1972a; Zimmerman et al., 1992; Kelly, 1999). Firstly, they developed a sense of community and a positive self identity in spite of the stigma that surrounds HIV. Openly living positive peers have also been able to develop and maintain a positive sense of self and become conscious and critical of HIV prevention. Secondly, via this involvement individuals affect change in their communities and make health interventions culturally appropriate and sustainable.

The major premise of community involvement, such as the activism of the peer activity group and the support members, is the development of appropriate and hence more effective prevention programmes. This is because individuals learn by doing, and by working together are able to mediate HIV/AIDS by transforming peer norms so that a positive self identity is socially supported by the campus community.

Thirdly, participation in peer activities and events develop group solidarity which counters feelings of alienation and low self worth. This is particularly important in terms of males who are often isolated and alienated from social support mechanisms. In the context of national prevention responses in which people living with HIV often are marginalized the HP project highlights the value of a multi-level approach.

The development of individual and collective strengths to increase the social capital of the community is a key strategy in mobilising them to address such complex issues such as stigma and gender equity.¹⁷ The study motivates for an up scaling of the HP project when one considers how effective the project has been in improving access to testing, treatment and care whilst also addressing issues of gender that impact on prevention.

The study further suggests that community led initiatives are sensitive to the needs, practices and desires of particular communities and therein lies the potential for successful

¹⁷ Chapter 2 (p.27) motivates why social capital is fundamental to the development of a health enhancing community in which people are able renegotiate gender identities that are congruent with improved sexual health.

prevention. An approach to community development that uses the principles of participatory action research is demonstrated by the HP project. These principles inform a mode of engagement in which people are able to use their own cultural and social knowledge to develop a project which is critical of itself and is constantly in the processes of making itself more relevant and democratising participation. This approach places emphasis on the value of critical reflection and informs the project how best to keep abreast of constantly shifting identities, practices, subcultures, and responses to prevention technologies, whilst insisting on the social and cultural dimensions of development in these contexts (see Kippax, 2008).

In conclusion the study proposes the need for an alternative process to traditional HIV/AIDS counselling. It has been noted that Western models of counselling which rely on an empathic process of exploring emotion and working through pain are not adequate in the African context (see Stein, 1996, Koo et al., 2006). The findings highlighted that most HIV positive people would prefer an approach that normalises HIV as a health condition and which encourages supportive community contexts. This highlights that there is need to create 'new systems' which are concerned not only with containing the spread of the epidemic but also address inequity within society (Kelly et al., 2001). This suggests that there is a need for a shift in focus from prevention which is concerned mainly with diagnosis of those who have HIV (and those who do not) towards deeper consideration of the norms that drive the epidemic. It is in revision of these norms that systemic change can begin to take place and individuals can begin to renegotiate their identity via the norms that govern their relationships.

LIMITATIONS OF THE STUDY

It may be too early to tell to what degree community-level initiatives can offer people living with HIV new repertoires for responding constructively to HIV/AIDS at a time when people with the disease are pathologised and blamed for the spread of the pandemic. The findings of this study suggest a model that has the potential to address this problem on a systemic level in higher education communities.

The question of whether or not the findings of this study can be extrapolated into larger community networks is beyond the scope of this study. More research is needed to ascertain the role of the HP project in campus outreach programmes in local communities. It is recommended that a stronger participatory action research approach be incorporated

into the design of such a research project. The researcher found that the nature of participation dynamics within this study's somewhat 'classic' qualitative research approach, was somewhat limiting. It is further suggested that management structures should be encouraged to actively participate in all aspects of the research process rather than being limited to commentary in informal conversations. It is believed that this would encourage all stakeholders to engage with the project in a more critical way.

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APPENDICES

1 DISCUSSION GUIDES

Exploratory group: Focus group discussion A

Experience of the HP project

[Prepared as part of the DramAidE Evaluation 2007/8]

Group:	Peer educators, HP project	No of students attending:	8/9
Venue:	DUT City Campus	Aggregate of gender:	4 males to 5 females (one female left early)
Date:	290807		
Duration:	12:00 – 14:00		

Facilitator: Welcome to today. I appreciate you coming...

1. "Have you worked with an HP?"
2. "Has it been helpful – can you tell me how it has helped?"
3. "Have you attended a DramAidE workshop?"

Probes: "Was it useful? In what ways was it useful?"

4. "Have you been able to replicate DramAidE workshops for prevention with your own groups?"
5. "Have you been able to replicate DramAidE workshops for promoting VCT with your own groups?"
6. "Have you done any HIV prevention work off campus?"
7. "Tell me about any prevention of VCT campaigns you have worked on?"

[END OF DISCUSSION GROUP]

Post workshop discussion 1: Goals and methods employed by the Health Promoter project in revising stigma and gender norms

Group:	Support group	No of	
Venue:	Boardroom	students	
Date:	151108	attending:	15
Duration:	60mins	Aggregate	4 males
		of gender:	9 females

Facilitator: "We will initially focus the goals and methods employed by the HP project."

1. "Let's begin with your understanding of the HP project and how you have experienced it on campus."

Probes: Do you think it has made a difference? What have been responses from management, staff and students? Where have you seen the HP make the greatest impact? What do you think the limitations of the project are?

2. "What was the context of HIV stigma and discrimination prior to the HP project?"

Probes: How do you think the project has influenced perceptions about HIV/AIDS? Have beliefs and attitudes changed on campus and to what do ascribe these changes? What methods are used to do this?

3. "In what ways, do people express their support of HIV/AIDS and values that reduce stigmatising attitudes?"

Probes: Where did you see this? How has it changed over the years? What kinds of prejudices are still experienced and who experiences them the most?

4. "What about staff? If we can talk about staff would you say they are involved with reducing gender and HIV prejudices?"

Probes: Is this different to how it was previously? Are there any experiences, activities or events on the campus that have influenced your attitudes or responses with regards gender and HIV?

5. "Do students and staff know their HIV status?"

Probes: What is the attitude to knowing HIV status? Do people participate in HIV/AIDS activities and events? How does it happen? What is the general attitude to VCT? Do they think that having HIV testing available makes a difference? Is there anything that makes testing easier?

6. "To what extent is your impression of what it is to be an HIV positive person at this institution?"

Probes: Do you think it is different for males and females who are HIV positive? How do males and females feel about finding out their status? Is it different for the different genders? Do people think about this critically? What are the possible reasons for this?

7. "What treatment options are available for staff and students?"

Probes: What would the experience of a staff member be if they disclosed their HIV status? Why do you think this is the response? Do staff members test at HIV/AIDS events? Is this different to how it was in the past?

8. "A last question, before we close: If we critically consider the goals of the project - do you think the HP project can build on the methods that it uses and maximise the opportunities that the intervention is presented with?"

Probes: What opportunities could the project build on? Are there any more thoughts or observations that you would like to make?

9. "Thank you for your participation."

[END OF DISCUSSION GROUP]

Post workshop discussion 2: Experiences of the Health Promoter project and outcomes that address HIV and gender prejudice for increased access to treatment

Group:	Support group	No of	
Venue:	Boardroom	students	
Date:	151108	attending:	15
Duration:	60mins	Aggregate	4 males
		of gender:	9 females

Facilitator: "We've just been doing some exercises which may have made you think and feel some things. Let's talk about these and what you experienced.

1. "What do you think the effect of the games that we played might be?" *Probes:* What games made an impact? Why? How does this relate to you and your peers? Why do you think this?

2. "Let's look at some of the relationship issues that were raised. What do you think are some of the issues facing students like yourselves? *Probes:* Are there differences between how males and females relate to each other? In relation to HIV/AIDS what are really important aspects that you would like to raise?

3. "To what extent do you think the HP project or HP engages students in discussing these issues?" *Probes:* Has the HP project had any effect in your everyday life? What are some of the experiences that you have had that you consider important?

4. "What kind of experiences have you had with the HP project and what role has the HP played in role in making a difference to experiences you might have had?"

Probes: How has this affected you? Was it a positive or negative experience? How do you see it now?

5. "How do people respond to HIV positive people on this campus?" *Probes:* Do you feel that you would have support? Who would you go to if you tested and found that you were positive?

6. “Do you think that males and females respond differently to an HIV diagnosis?” *Probes:* How would they respond? Why do you think this is? Do you think that this would be different amongst other social groups on campus? For example, if you were not involved in the HP project or lived in residence?

7. “What are the challenges that males and females face in seeking treatment that are influenced by their perceptions of who they are as a “man” or “woman”?” *Probes:* On this campus what would most men or woman students do if they thought they were HIV positive and needed treatment? Would your responses be different to theirs? If so, what empowers you to act differently?

8. “Do you think that you are better able to handle relationship issues or situations that are challenging?” *Probes:* For example, what would you do if you found out that you or a close friend was positive? Prior to your experience of the HP project would your response have been different?

9. “What are the things about the HP project and the way in which the HP works with you that you most or least enjoy?”

10. In conclusion: What do you think the key things have been about this project that have helped males and females to think differently about things like HIV testing, prevention, treatment and care?”

Probes: Is it the personality of the Health Promoter? How is the project run or facilitated? Do you think that you would be able to use this approach in your own lives and communities?

11. “Do you have any other thoughts or observations that you might like to make?”

12. “Thank you for your participation.”

[END]